DOCUMENT RESUME

ED 466 621 CE 083 354

AUTHOR	Wilson, Kathleen K.
TITLE	Promoting Health Literacy.
INSTITUTION	Clemson Univ., SC. Inst. on Family and Neighborhood Life.
PUB DATE	2001-00-00
NOTE	71p.; Project Contributor, Shirley McNabb. Published with the J. Marion Sims Foundation, Inc., Lancaster, SC. Partially supported by the South Carolina Collaborative on Grassroots and Nonprofit Leadership. A What Works report supporting the J. Marion Sims Foundation's Defining Futures Adult Literacy and Basic Skills Development Strategic Giving Initiative and the South Carolina Center on Grassroots and Nonprofit Leadership's Literacy Program Initiative.
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	EDRS Price MF01/PC03 Plus Postage.
DESCRIPTORS	Adult Education; *Adult Literacy; Community Planning; Community Programs; Definitions; Disabilities; Educational Needs; Educational Objectives; Evaluation Methods; *Functional Literacy; Guidelines; Health Education; *Health Promotion; Higher Education; Information Dissemination; *Instructional Development; *Integrated Curriculum; International Programs; Learning Processes; Limited English Speaking; *Literacy Education; Models; National Organizations; Nonprofit Organizations; Outcomes of Education; Partnerships in Education; Private Sector; Program Evaluation; Public Agencies; Student Evaluation; Teaching Methods; Volunteers
IDENTIFIERS	*Health Information; South Carolina

ABSTRACT

This document is designed to help literacy practitioners and others establish health literacy programs to help learners in South Carolina develop the literacy skills needed to perform their role as health consumers and providers and maintain their own health and the health of those they love. The introduction defines literacy and health literacy, explains how health literacy is measured, and outlines issues connected with health literacy. The following types of health literacy initiatives are described: public agency partnerships; health literacy information models; nonprofit lead examples; health literacy volunteer efforts; private health provider settings; international efforts that support local efforts; models for increasing readability and understandability of health messages; and higher education models. The following strategies for success are discussed: determining local community health issues; identifying a program vision and determining outcomes based on that vision; building necessary partnerships; using effective adult teaching and learning principles; designing and implementing a health literacy evaluation program; and building a health literacy public awareness campaign. A section on available health literacy resources includes annotated listings of 29 organizations and 4 publications. A discussion of the impacts of nationally and locally low health literacy and 13 principles of effective educational practice are appended. (Contains 21 endnotes and references.) (MN)

Promoting Health Literacy

A Report of the
Institute on Family and Neighborhood Life at Clemson University
and
J. Marion Sims Foundation, Inc.

CLEMSON
UNIVERSITY
Public Service Activities
Research • Extension • Regulatory

Promoting Health Literacy

Principle Author

Kathleen K. Wilson, Ph.D.
Professor and Director
Center on Neighborhood Development and
South Carolina Center on Grassroots and Nonprofit Leadership
Institute on Family and Neighborhood Life
Clemson University
158 Poole Agricultural Center
Clemson SC 29634-0132

Project Contributors

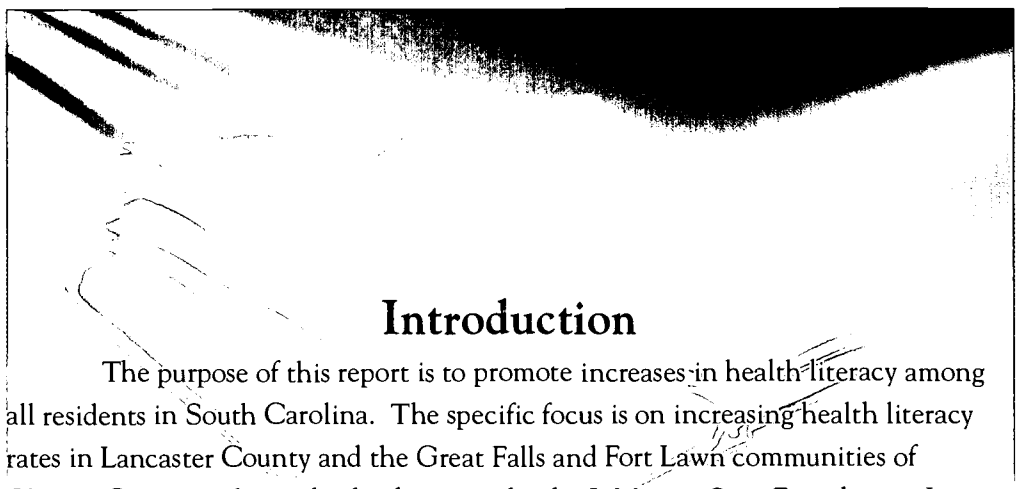
Shirley McNabb
Research Associate
Institute on Family and Neighborhood Life

This is a publication of the Institute on Family and Neighborhood Life at Clemson University and of the J. Marion Sims Foundation, Inc. in Lancaster SC. It was partially supported by a grant from the J. Marion Sims Foundation and The South Carolina Collaborative on Grassroots and Nonprofit Leadership. It is one of the What Works reports supporting the J. Marion Sims Foundationís Defining Futures Adult Literacy and Basic Skills Development Strategic Giving Initiative and the South Carolina Center on Grassroots and Nonprofit Leadershipís Literacy Program Initiative.

Fall 2001

CLEMSON
UNIVERSITY
Public Service Activities
Research • Extension • Regulatory

Table of Contents
Promoting Health Literacy



Introduction

The purpose of this report is to promote increases in health literacy among all residents in South Carolina. The specific focus is on increasing health literacy rates in Lancaster County and the Great Falls and Fort Lawn communities of Chester County. This is the funding area for the J. Marion Sims Foundation, Inc. This report is written for those wishing to create caring communities that support health literacy skill development so that everyday healthy living is enhanced. It is particularly focused on literacy development for adults in their role as health consumer and provider, and in their efforts to maintain their own health and the health of those they love. Other reports are available that discuss literacy skill development related to being an effective worker, citizen, parent and family member.

Having low health literacy is extremely costly. It is an insidious barrier to being healthy. The lack of general literacy in a large portion of the population of the United States, including South Carolina, means many are unable to effectively access and use health care services. The high rate of low health literacy among the adult population is estimated to cost $73 billion dollars in 1998.[1] If there was one area of community improvement that could decrease the cost of government and community expenditures and increase the quality of life in America, it would be to tackle our health literacy issues in America and create health literacy learning and communication systems that are effective.

Community leaders who improve health literacy levels are involved in two primary literacy education tasks: improving literacy skills in general and health literacy skills in particular. They are related skill sets but not the same thing. Therefore, we begin with a review of literacy skill development in general and how these skills have been measured. This discussion is followed by a description of what health literacy skills are and how they are measured.

Engaged community leaders also understand how to build a seamless health literacy system that supports health providers and adults who wish to increase their health literacy skills, knowledge and communication practices. Therefore, model efforts are reviewed. Help is provided on how to start health literacy initiatives. Resources are reviewed to assist readers in accessing quickly needed resources.

Since health promotion efforts might be confused as health literacy efforts, this report begins by defining what literacy is so that readers can understand the differences between a health literacy initiative and a health promotion initiative in general.

What is Literacy?

The National Institute on Literacy defines literacy as the ability to read, write, and speak English proficiently, to compute and solve problems, and to use technology in order to become a life-long learner and to be effective in the family, in the workplace and in the community.[2]

The ability to read, write, to understand and be understood are critical to personal freedom, the maintenance of a democratic society, the broader goals of economic opportunity and security, social justice, human dignity and personal well-being. Approximately half of America's adults were not functionally literate in 1993, the last time a national survey was conducted. That percentage equals approximately 90 million adults. Very few adults in the U.S. are truly illiterate. Rather, there are many adults with low literacy skills who lack the foundation they need to find and keep a decent paying job, support their children's education, maintain their health, and participate actively in civic life.

In Lancaster and Chester counties it is estimated that 68% of the Chester County population has level 1 or 2 literacy proficiency and that 60% of Lancaster County's population is at this same level. These levels will be explained below, but for now the point is that both counties are above national and state averages in low literacy rates. We shall see as we go along that this current situation is having many costly effects.

All adults need four literacy skill sets. These 4 categories of skills are used in combination in order to carry out effectively everyday activities as a parent, worker, citizen, and health consumer and provider.[3] They are reviewed in Table 1.

Table 1. Basic Literacy Skills Needed By All People

Communication Skills
Read with understanding
Convey ideas in writing
Speak so others can understand
Listen actively
Observe critically
Decision Making Skills
Solve problems and make decisions
Plan
Use math to solve problems and communicate
Interpersonal Skills
Cooperate with others
Guide Others
Advocate and Influence
Resolve conflict and negotiate
Lifelong Learning Skills
Take responsibility for learning
Learn through research
Reflect and evaluate
Use information and communications technology

The implications and impacts of such staggering numbers of low literacy rates in the U.S. population are many. 43% of people with the lowest literacy skills live in poverty. Over 75% of current welfare recipients have very low or low reading skills. Only 30% of adults with very low literacy skills have full-time jobs. Some have part-time jobs, but over half of these adults no longer look for work. Nearly one-third of prison inmates has very low literacy skills. Another 40% are barely able to read. Every aspect of life is affected by such high rates of low literacy skills. Forty million adults find it a struggle to read to their children or help with their homework. They cannot understand health instructions.[4] Everyday tasks are beyond their skill levels.

How Is Adult Literacy Measured?

When literacy was simply thought of as reading, it was typically measured in grade-level equivalents. An adult's literacy skill was said to be at a first grade or fifth grade level, for example. A more complex, more realistic conception of literacy emphasizes its use in adult activities. To determine literacy skills in American adults ages 16 and older, the 1992 National Adult Literacy Survey (NALS) used test items that resembled everyday life tasks. It involved the use of prose, document and quantitative skills. The NALS classified the results in five levels of proficiency with level one being the lowest level of proficiency and level five being the highest. These levels are now commonly used to describe adult literacy skill levels.

The *prose literacy* items assessed the adults' ability to handle written text such as editorials, news stories, poems and fiction. It assessed the ability to handle both expository and narrative prose. Expository prose involves printed information that defines, describes, or informs such as newspaper stories or written instructions. Narrative prose assessed the adults' ability to understand a story. Prose literacy tasks included locating all the information requested, integrating information from various parts of a passage of text, and writing new information related to the text.

Document literacy items assessed the adults' ability to understand short forms or graphically displayed information found in everyday life, including job applications, payroll forms, transportation schedules, maps, tables and graphs. Document literacy tasks included locating a particular intersection on a street map, using a schedule to choose the appropriate bus, or entering information on an application form.

Quantitative literacy information was displayed visually in graphs or charts or in numerical form using whole numbers, fractions, decimals, percentages, or time units. These quantities appeared in both prose and document form. Quantitative literacy referred to locating quantities, integrating information from various parts of a document, determining the necessary arithmetic operation, and performing that operation. Quantitative literacy tasks included balancing a checkbook, completing an order form and determining the amount of interest paid on a loan.

The National Adult Literacy Survey (NALS) captures well the printed and written information dimensions and related reasoning skills but is not as complete as the National Institute for Literacy's *Equipping for the Future* competency standards for adult literacy. These standards also include the communication, interpersonal relationship and life-long learning dimensions to literacy development. The *Equipping For the Future* standards are reviewed later in this report.

Almost all adults in Level 1 can read a little but not well enough to fill out an application, read a food or medicine label, read a simple story to a child or fill out a deposit slip correctly. Adults in level 2 usually can perform more complex tasks such as comparing, contrasting or integrating pieces of information, but usually not higher level reading and problem-solving skills. For example, those at level 2 could correctly write their signature on a social security card and fill out a simple job application. However, they could not read correctly a sales graph or figure out what the gross pay was on a pay check stub or add correctly the cost of a meal. Adults in levels 3 through 5 usually can perform the same types of more complex tasks on increasingly lengthy and dense texts and documents. These levels use a broad range of information processing skills in various combinations. For example, people at level 3 could figure out bar charts and graphs but could not correctly read a bus schedule. They could not figure out the correct number of minutes that it would take to get from one location to another. People at level 4 could read the bus schedule but not summarize the views of parents and teachers found on a summary chart which involved comparing parent and teacher data across four questions and across three levels of schools. They could not correctly estimate the cost per ounce of a food product when given a food store shelf label with this information on it or figure out interest charges on a home loan.

In summary, each scale was divided into five levels that reflect the progression of information-processing skills and strategies. These levels were determined, not as a result of any statistical property of the scales, but rather as a

result of shifts in the skills and strategies required to succeed on various tasks along the scales, from simple to complex.

For a review of the levels of literacy found in the National Adult Literacy Survey see http://nces.ed.gov/naal/ . This site also contains samples from the survey instruments.

Many factors explain the relative high number of adults in the lowest level of literacy. 22% of adults in Level 1 were immigrants who may have just been learning to speak English. More than 60% didn't complete high school. More than 30% were over 65. More than 25% had physical or mental conditions that kept them from fully participating in work, school, housework, or other activities and almost 20% had vision problems that affected their ability to read print.[5]

What is Health Literacy?

Health literacy is "the capacity of an individual to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which are health-enhancing."[6]

Patients are often faced with complex information and treatment decisions. They are asked to evaluate information for credibility and quality. They must analyze relative risks and benefits, calculate dosages, interpret test results and locate health information to make wise decisions. In order to do so, an adult must be visually literate (able to understand graphs or other visual information), computer literate (able to operate a computer to search for information), information literate (able to obtain and apply relevant information) and numerically or computationally literate (able to calculate or reason numerically). Oral language skills are important as well. They have to be able to articulate health concerns and describe symptoms accurately. They need to ask pertinent questions. They need to understand spoken medical advice or treatment directions. In an age of shared responsibility between health providers and patients for health care, patients need strong decision-making skills. Even those highly literate in other areas of life face challenges in the health literacy area.

Both health providers and the consumers are responsible for having functional health literacy competencies. Each has important roles and responsibilities. As consumers, we all must learn to be health literate. And given certain circumstances, our health literacy skills may be too low or we may not know how to use them. Some situations will require more learning in order to function adequately, thus testing our lifelong learning literacy skills. We can be literate in all other aspects but still not be functionally health literate. However, those with low literacy levels are particularly vulnerable to also having low health literacy. *In Lancaster and Chester counties over half of the adult population is expected to have inadequate health literacy competencies, based on national averages.*

Health care providers also have roles and responsibilities for insuring a health literate population and in dealing with those that are not health literate. There are professional and volunteer providers. Family members, friends, nurses, doctors, health educators, pharmacists, and public health practitioners also play a role in health literacy practice. So the health literacy field has created help for consumers and caregivers. Some resources listed in this report are aimed at consumers and others are aimed at health providers in public and private settings.

"I went to a clinic with my husband. He thought he had the symptoms of meningitis. He was a doctor in Venezuela. He knew a great deal about this disease. When he mentioned his background and his diagnosis to the nurse and the doctor, my husband suggested that he have a MRI. He was told to go home and take a few aspirins. Late in the evening after waiting in the clinic all day and being told to go home, his symptoms became worse. He returned to the clinic. Finally the doctor gave him a referral to a nearby hospital for a MRI scan. As he expected, the results of the scan came back positive. The doctor told him that if he had waited much longer he could have died."

The National Institute for Literacy is charged by the U.S. Congress to develop standards for leaders to use to equip adults with literacy skills needed to effectively carry out primary adult roles of parent, worker, citizen and health consumer and provider. When the National Institute produced the *Equipping for the Future Standards (EFF)* report for Literacy, a role map for health literacy competencies was not done.[7] Health literacy professionals developed this area after the EFF standards were produced. Since then, the Eastern LINCS system, managed by the National Institute for Literacy, has adopted health literacy as a special focus of their development work on behalf of the national literacy system. Their work has helped communities add the health literacy area of concentration to their efforts. In the future, there will probably be a role map for health providers and consumers. In the meantime, health maintenance tasks are found in all three current role maps (i.e. parent, citizen and worker) found in the *Equipped For the Futures* report.

For each role, key everyday living tasks common across these roles were identified. These tasks were seen as ones that endured through time and across the various roles. They are the building blocks of being a literate adult as parent, as worker, as citizen, as health consumer and as provider. The 13 everyday activities related to being health literate are found in Table 2. These 13 activities are primary competencies used to consume effectively health information and services and provide effective health care for one's self and others.

Table 2. 13 Everyday Literacy-related Health Consumer and Provider Activities

1 **Gather, analyze and use health information**
(Find and analyze information from diverse sources. Use it to form opinions, make decisions, and take action.)
- Monitor and gather information from a variety of sources
- Establish criteria for the quality and appropriateness of the information
- Assess the value of the information
- Use the information to make informed decisions

2 **Manage resources**
(Find, manage, share, and allocate time, money and material resources in a way that supports your own health needs, goals and priorities and those of your family, community and workplace.)
- Identify those resources you have and those you need
- Determine where they are and how they can be obtained
- Use the resources in an efficient and effective manner
- Balance resources effectively for family, work, community and self

3 **Work within the big picture**
(Look beyond the immediate situation. Take into account the structures, culture, practices, and formal and informal rules and expectations of the health care systems that influence and shape your health care actions.)
- Gather information about a system and how it works
- Determine your relationship to the system and the roles you and others play within it
- Monitor the system and predict changes
- Base your efforts to influence the system on your knowledge of how it works

4 **Work together**
(Cooperate with others to learn, accomplish tasks and pursue common health related goals.)
- Identify what needs to be done and plan how to do it
- Pay attention to the relationships within the group as well as to completing the task
- Identify and draw upon everyone's strengths in carrying out the work of the group
- Recognize and deal with conflict in a productive manner

5 **Provide leadership**
(Inspire and direct others in shaping and achieving a common health goal.)
- Institute and manage plans for action and change based on an understanding of the big picture
- Organize and motivate others to act
- Guide sound problem solving and decision making
- Assure consistent monitoring and evaluation of performance

6 **Guide and support others**
(Help others succeed by setting an example of healthy living, providing opportunities for learning, or giving other kinds of assistance.)
- Acknowledge and reward others' strengths and accomplishments
- Contribute to creating supportive, learning environments and experiences
- Empower others through mentoring, coaching and being a role model

7 **Seek guidance and support from others**
(Help yourself succeed by asking for information, advice and assistance.)
- Recognize when you need help and know where to go for it
- Seek out relationships with people whose judgment is trusted
- Create and make use of networks of personal and professional contacts
- Be responsive to new ideas and accept and use constructive criticism and feedback

Table 2. 13 Everyday Literacy-related Health Consumer and Provider Activities (cont.)

8 **Develop and express sense of self**
(Create you own personal voice in healthy living. Use your understanding of self to guide your health care actions.)
- Examine and clarify your own values and beliefs, recognizing the role your cultural heritage and personal history play in shaping these and in determining the possibilities of expression
- Maintain standards of integrity
- Consider the constraints of the situation as well as your own strengths and weaknesses when choosing a course of action
- Pursue outlets for interests and talents to maintain emotional and physical health

9 **Respect others and value diversity**
(Respect and appreciate the values, beliefs, cultures and history of others. Use this understanding to counteract prejudice and stereotypes.)
- Create an environment where others feel welcome, are included and thrive
- Encourage and carefully consider a wide range of opinion and beliefs
- Educate yourself about other cultures
- Challenge the beliefs that a person's inherent capacity is limited by background or group membership.

10 **Exercise rights and responsibilities**
(Act and advocate on behalf of yourself and others, taking into account laws, social standards, and cultural traditions.)
- Recognize and assume your share of family, civic and work responsibilities
- Monitor and keep up to date on federal, state and local laws and regulations
- Make sure your own behavior is just and responsible
- Take personal responsibility to bring about change or resolve problems to achieve a common good

11 **Create and pursue vision and goals**
(Dare to dream. Be clear about where you want to go to be and maintain health and well being and how to get there.)
- Articulate a vision that embodies your values and goals or those of your family, community or work group
- Establish attainable goals that are compatible with that vision
- Develop a realistic plan to move toward the vision and goals
- Create alternative means of meeting your goals that anticipate the effects of change

12 **Use technology and other tools to accomplish goals**
(Be familiar with a variety of tools and technologies that can make it easier to achieve your health goals.)

- Keep up-to-date on developments in tools and technologies that may be useful for communicating, managing information, solving problems and carrying out daily tasks
- Determine which tools are most useful for the purpose and context at hand
- Use complex tools, machines and equipment to solve problems

13 **Keep pace with change**
(Anticipate, manage and adapt to change in health conditions and systems that affect your life.)

- Adjust your goals and plans over time to take into account actual or prospective changes in health
- Keep abreast of and evaluate trends in the health care industry and community, as well as the nation and world
- Determine what skills and knowledge are needed to meet emerging health needs or new situations
- Create opportunities to expand your own skills and knowledge, as well as those of your family, community and work group.

How Is Health Literacy Measured?

Health literacy levels are determined by using the Test of Functional Health Literacy in Adults (TOFHLA). The TOFHLA enables health professionals to determine patients' general level of health literacy in numeracy and reading comprehension. These skills are necessary for patients to understand and follow healthcare providers' instructions. Without these skills, patients have difficulty following instructions accompanying medications, reading reminder cards for a clinic appointments and understanding issues involved in signing informed consent documents. TOFHLA is available in both English and Spanish versions, regular and large print, and in a short version. It is the most widely used way of determining health literacy levels.[8]

There were also health-related questions found in the National Adult Literacy Survey. The 2002 survey will contain an entire section on health literacy. In addition, The Comprehensive Assessment and Accountability System, (CASAS) is an assessment which measures health literacy. The CASAS assessment correlates highly with NALS results. In other words whether one uses CASAS or NALS the health literacy rates will be comparable. Health professionals and health care facilities most often use the TOFHLA survey to determine health literacy rates.

What Issues Are Connected with Health Literacy?[9]

Five critical issues are related to having a significant portion of the adult population with low health literacy skills. Some of the frequently reported statistics and facts related to these issues are reviewed in the Appendix. Sources upon which this section is based are identified in the endnotes.

Low health literacy contributes to higher use of health care and related services. When people do not understand health care instructions or live a healthy lifestyle, they are more at risk for adverse health consequences. This results in an increased use of health care services. In addition, there is higher risk of becoming ill more often and more acutely. This places one at higher risk for unemployment, which in turn is related to a higher risk of substance abuse and domestic violence, all of which requires ever more services—expensive services.

Economies can become dependent on low literacy rates, including low health literacy rates. The market place can become organized to survive off the ills and low capacity of low literacy people. Such economic growth is not the best way to grow the economy or create communities with attractive quality of life features.

Counties with low health literacy populations have an added and unnecessary economic burden. Everyone pays an increased cost for low literacy skills within a community. Taxpayers pay more taxes to fund services. Businesses pay more for health insurance premiums and experience less productivity. Consumers pay more for health care. More of limited state and county government resources are diverted to serving the consequences of low literacy behaviors.

Hospitals and insurance companies pay more for services and thus charge more. Businesses are more at-risk for malpractice claims. For example, national studies have shown a great deal of Medicaid costs for children and youth are associated with low literacy rates of parents and other health care providers. Lancaster and Chester counties are paying a high price. Using a conservative estimate based on national averages, both Chester and Lancaster County hospitals and consumers could have saved 3-4 million dollars each last year, if adult literacy rates were higher in both counties.

Low health literacy disproportionately affects the most vulnerable populations. People with disabilities, those living in poverty conditions, those speaking English as another language and seniors have special health literacy issues and challenges. These groups, on average, have higher rates of low health literacy than the general population.

Learning a new culture is always challenging. Adults who speak other languages besides English must become literate about a health care system that is both new and complicated. They must try to understand what is being said and learn how to problem solve in ways that are strange, unfamiliar or contrary to practices back home. Additionally, seniors with multiple medical conditions and slowing cognitive processes are similarly challenged.

The disproportionate effect of low literacy rates can be seen in the emergency room visits and in hospitalization of seniors and low-income families in Lancaster and Chester counties.

Literacy services are fragmented and uncoordinated across public agencies and between public agencies and nonprofits. South Carolina is working to raise literacy levels. It is important to raise health literacy skills within the context of the broader literacy education efforts currently going on in South Carolina. The National Literacy Act, which became public law in 1991, laid the foundation for states to develop strategies to improve literacy rates.

During this past decade, states develop the necessary state components, including their state's literacy resource center that are required by the National Literacy Act of 1991.[10] States vary in how effective, influential and strong their literacy education efforts have been. This variance is largely due to the leadership present and their understanding of the importance of increasing literacy rates in order to have a sound economy, environment and healthy communities.

The current status of South Carolina's efforts to take advantage of opportunities made available in the National Literacy Act may be best described as incomplete. At this time, there is no coordinated effort to bring together the disparate literacy promotion efforts being undertaken by different state agencies, different educational systems and independent private organizations. What efforts are being done lack meaningful evaluation data, so there is little evidence of effectiveness. There is a specific need to coordinate fragmented efforts of the state and county departments of education, commerce, employment security commissions, social services, mental health, and health. These efforts also need to be coordinated with those occurring in the nonprofit sector. More initiatives need to be developed all across the state.

One can be literate in all other aspects and still have low health literacy skills. To be functional implies that information and services are used so that one's health is maintained and enhanced. However, what we know may not affect what we do to be healthy. To compound the issue, the health care system is sufficiently complex that at times it baffles most of us. When emotional trauma is present during life-threatening situations, one's abilities to be a self-learner, and to put together, retain and use information correctly are greatly challenged.

To summarize, low health literacy skills

- exist among the educated and uneducated.
- exist among the rich and poor.
- are dangerous to your health!
- threaten the health and well being of children.
- sabotage appropriate medical treatment.
- undermine health promotion efforts that rely on printed communication.
- reduce one's ability to access health care and get insurance.
- result in poor health behaviors.
- have a severe economic consequence to society.
- add to everyone's state and federal tax burden.

While some do, community leaders can not afford to ignore high rates of low health literacy and low literacy skills in general. It simply costs us all too much personally and collectively.

What Do Health Literacy Initiatives Look Like?

In the health literacy field there are several different kinds of health literacy models from which to learn. Some target the health professional. Others target the population at large. Some incorporate health content into general literacy learning contexts. Others help health providers and agency leaders effectively communicate health content to adults with low literacy. Still other programs effectively apply functional literacy skill development to health maintenance behavioral learning and to situations where literacy skills are needed to cope with disease and illness.

Health literacy initiatives are lead by public agencies and private for-profit and non-profit agencies. Some of each is reviewed in the following section. Still others are good examples of partnerships of various kinds in which scare resources are shared and leveraged.

The purpose of this section is to provide a menu of possibilities for leaders to learn from and to enhance the number and effectiveness of health literacy education efforts in their community.

Examples of Public Agency Partnerships

The Massachusetts State Adult Basic Education Services (SABES) Health Literacy Initiative. Five years of innovative and creative work done by the Massachusetts Department of Health integrated health education into Adult Basic Education (ABE) and English for speakers of other languages (ESOL) activities throughout the state. As a result Massachusetts is considered the national leader in the development of organizational mechanisms, programs and resources on health literacy. They have created the necessary help for directors of adult learning centers and teachers of ABE/ESOL settings to effectively incorporate health literacy learning experiences into what they do. Curriculum materials are available on line. Helps in fostering health collaborations in communities so that health literacy issues are addressed are also available on line. They have created 10 regional centers that are collaborative partnerships among public agencies and nonprofits. It is the most well developed example of good articulation between the departments of health, education, labor, the technical colleges, nonprofits and private health care providers. The state's literacy councils are also involved with these centers. This initiative provides a good model of what could be done at the county, as well as the state level. With the support and understanding of each center director, teachers use health as a content area in all the center's programs—family literacy, ESOL, workplace education, pre-GED and GED, skills training, parenting. (See http://www.sabes.org/ The SABES Health Page is particularly rich with idea and resources.)

Local Health Literacy Collaborations. Adult, health, and workforce educators understand the need to communicate and collaborate so that community health resources, services and information are available to adult learners. These

educators tend to target the same populations. As mentioned above, Massachusetts organized their efforts around 10 prevention centers located throughout the state. Each provides consultation, training, and education in the area of public health, literacy and community development. They house extensive resource collections and services.

Other communities incorporate health literacy initiatives as a part of their healthy community initiatives. Others have taken the National Literacy Volunteer model and created a community volunteer system to organize resources and support needed for all adults in the community to have the kind of help they need.

Georgia's Certified Literate Community Program (CLCP). Georgia's Department of Technical and Adult Education has developed a Certified Literate Community program with the goal of improving the literacy levels of half of the adult population in each Georgia community during a 10-year time frame. While this is a new initiative, it looks very promising. The idea is simple but one that community leaders can get behind. They are targeting communities with the capacity to initiate programs to help low literate individuals. (That is, this initiative is aimed at communities having enough social capital present so that leaders effectively work with one another, share resources and enhance a variety of settings.) The program is working to bring business, health, education and community leaders together. See their site at http://www.dtae.org While the model is aimed at increasing general literacy competencies of the adult population, one can see the possibility for a certified health literate community program.

The National Network of Libraries of Medicine promotes the role of **consumer health librarians** and provides help to encourage librarians' active involvement in health literacy efforts at the community level. They find that many consumer health literacy initiatives are geared toward technological access to health information or rewriting existing health materials at a simpler language level. They suggest these approaches are important but limited in result and are only pieces of a process that must be placed in a larger community context. They suggest that consumer health librarians can actively develop partnerships between literacy groups, community organizations and health care associations. They can provide space for meetings, health literacy materials or actively develop health literacy programs. They can promote awareness of health literacy among health professionals by creating clearinghouses of health literacy information, sponsoring health literacy seminars and encouraging multi-organizational collaborations. The National Network of Libraries of Medicine, South Central Region which is part of the Houston Academy of Medicine, Texas Medical Center Library is leading the way and has good information to those librarians that want to become actively involved in health literacy efforts. (See http://www.nnlm.nlm.nih.gov/scr/conhlth/hlthlit.htm for further suggestions and resources.)

Health Literacy Information Models

The Eastern LINCS Special Health Collection. As explained elsewhere in this report, the United State's literacy resource system is now organized at the state, regional and national levels. At the regional level, there are regional literacy information service centers called LINCS. (See http://www.NIFL.org for details.) The Eastern LINCS center is known for its health literacy development. There are online lesson plans and student project ideas. For community leaders just getting underway with health literacy instruction, this will be a very important resource for you.

Also see the World Education's ***Health and Literacy Compendium*** described below in the national efforts supporting local efforts section.

Nonprofit Examples

Infant Welfare Society of Chicago is a nonprofit primary health service center mainly for indigent Hispanic women and children. The clinic provides pediatric care, pediatric dental care, women's health care including reproductive health and well woman care, health education and mental health services. All services are on a sliding fee scale; no one is denied service. They are involved in providing plain language materials to their participants as well as increasing reading levels of children and parents. This clinic introduced a reading program that provides bilingual books for parents of children when they come in for their physical exams. Volunteers are in the waiting rooms to model effective reading and listening times. Reading is approached as a story telling session and parents are encouraged to talk about the pictures in the books with their children. They established a book club for the older children and each year the clinic holds a Reading Fiesta. This event keeps families reading over the summer. They also hosts a street fair. The fair provides opportunities to get out a variety of health messages. The clinic also collaborates with the City of Chicago's Bookmobile program. The bookmobile goes to the neighborhoods in which the clinic's patients live. They also have a partnership with an adult literacy provider, Literacy Chicago, and the West Town Public Library. This partnership offers ESOL class on site during clinic hours and provides family literacy and library literacy activities. The ESOL curriculum contains health literacy modules, how to interact with the public schools, how to access medical services, how to go to the store and how to take public transportation. Parenting and nutrition information is the content around which EOSL instruction is done. (See http://www.infantwelfare.org)

The Gathering Place and Navajo Co-op Store is a good example of creating a health literacy program that meets the needs of a specific cultural group. The Gathering Place is a nonprofit family center that focuses on family literacy, health awareness and economic development in the Eastern Agency of the Navajo Nation. Local women who are peers of the participants served by the center offer services.

They share their language, culture and reality, and thereby bring culturally sensitive compassion and insight into the health literacy learning experiences. There are several literacy emphases. One emphasis is on literacy learning through sharing cultural traditions. Another is on English as a second language learning. Another stresses Parents as First Teachers, (which is a key component of effective family literacy programs) and aims to increase the reading skills and education of participating parents, and increase the time parents spend with their children. The ultimate goal is to end the intergenerational cycle of under-education and poverty prevalent in their service area.

They also have WIC clinics, pre-schools, battered women's shelters, and tribal houses. Their wellness programs combine literacy development with health, safety, mental and physical wellness and preventive health maintenance measures. You can visit their site as http://www.navajo-coop.org/.

"My mom is a shaman (medicine woman) in Mexico. As a child she gave me all sorts of home remedies. For a common cold she would give me a compress to wear under my clothes. When my schoolmates noticed the compress they teased me a lot. I had few friends. Few wanted to be with me because they knew I had different medical and spiritual practices. When we went to the doctors in this area they never asked about what we did at home to treat our illnesses. Sometimes I think what they gave me and what my mom gave me caused me to get sicker rather than better. I don't know but I wonder."

Advance, Inc. is a leading nonprofit model that combines worker, family and health literacy efforts into an integrated family center. ADVANCE started out in San Antonio, Texas and is now a recognized pioneer in the field of comprehensive, community-based services for very high-risk Spanish-speaking families. It is one of the country's oldest and largest programs supporting and educating parents of children under three years of age. It has centers all over Texas and now, with the help of funding from Kellogg and Casey Foundations, the model is being replicated in other communities throughout the United States. This is one of the most comprehensive program models available to follow. See http://www.avance.org/ for a description of their entire literacy emphasis including health literacy. See http://www.latino-net.org/avance/history.htm for the AVANCE Kansas City model.

Bethel New Life is a model for several effective practices, including health literacy. It is an example of a church-based effort that saw the vision for how to transform their neighborhood surroundings on the West Side of Chicago. It now has a national reputation for innovative approaches to community economic development in a predominately low-resourced African American community. One of their efforts was to engage local neighborhood residents in a discussion process through which they identified key indicators of what they thought was related to helping them become healthier. In this case, health literacy learning opportunities

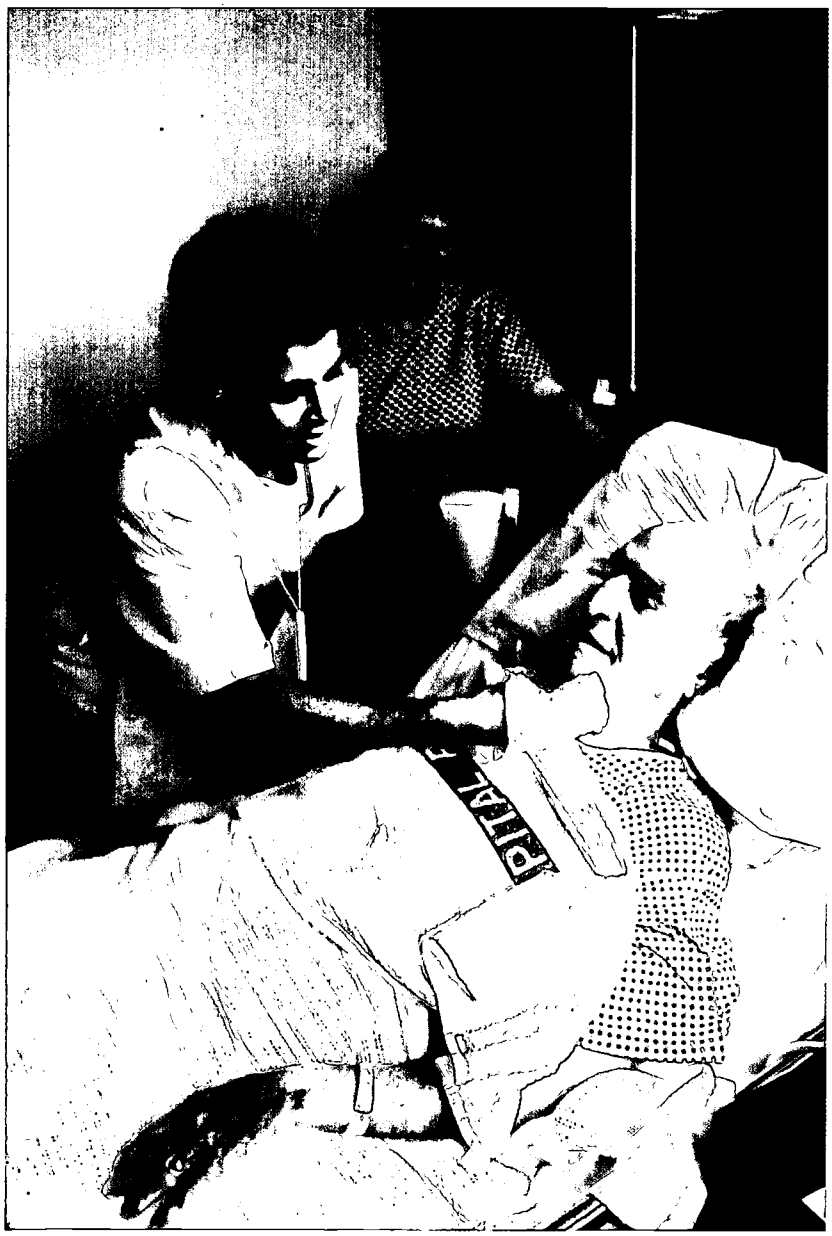
are seen in the larger context of creating healthy, sustainable communities. (See http://www.healthforum.com/hfcomhealth/asp/act_summary.asp for a description of some of their work.) While this is an urban model, for all practical purposes what they did could be done in a rural setting. When they started out they had virtually few resources at their disposal. Their story of how they organized is both inspiring and instructive. Creating and sharing a plan of action is key to the success and the involvement of local residents. See their latest strategic plan and more about all they are doing at http://www.bethelnewlife.org/

Healthwise Communities is a partnership model that was started in Boise Idaho but several states have used their work as a base to begin their own. Anderson, Oconee and Pickens Counties in South Carolina and Hart County, Georgia drew from the Boise model to develop a similar effort. The Partners for a Healthy Community located in Anderson received grants that allowed them to mail each household in four counties a *Healthwise* Handbook. This handbook deals with over 180 health topics and is designed to help adults think through health questions. The handbook coaches people on how to connect with the health care community in effective ways. The handbook, however, is written for a fairly high reading level which limits its audience and its usefulness. Where reading literacy is higher, even though other health literacy skills may be lower, the handbook will be useful. The Partners also have a 1-800-phone line managed by nurses, called Partners Nursewise Line, so that those who need health related information and advice can access a nurse. This oral communication mechanism helps reach out to those who might not be able to read the Handbook. They also have a *Healthwise Knowledgebase* that is accessible through their web site. (See www.healthy-community.org and click on the Healthwise Knowledgebase icon.) This obviously is for adults with higher literacy skills. Topics included deal with questions frequently asked by local adults, such as what to do if you have insomnia, how to be good to your back (which is one of the top reasons why people are visiting the hospital in the area), communicating with your doctor, depression and avoiding diabetes. Through this same effort, the Partners offer community workshops on a variety of topics.

Healthwise, Inc. the parent company that started all these resources is now a nonprofit organization committed to creating self-care and shared decision-making tools from technical medical information. Their mission is to help people do a better job of staying healthy and taking care of their health problems. They believe that wise health decisions involve three things: A *mindset* to take an active role in one's own health; a *skillset* to do self-care and shared decision-making; and a *toolset* of information to understand health options.

Health Literacy Volunteer Efforts

In some communities the resources may be scare enough to only be able to think about what to do without the benefit of any additional financial resources or paid staff. In such cases, think about a volunteer health literacy project. Churches can partner with the local literacy council on such efforts. Using volunteers helps lower costs of services, provides more flexibility in providing services and instruction, is more personalized, is less threatening and provides more opportunities for mentoring and individualized instruction. The pace of learning can be more flexible and a greater range of services is possible for those requiring non-traditional education. Several organizations provide volunteers. It may be that your leadership could develop a partnership with one or more of these organizations. They include the Corporation for National Service (http://www.cns.gov), AmeriCorps (http://www.americorps.org), Learn and Serve America (http://www.cns.gov/learn/), National Senior Service Corps (http://www.fostergrandparents.org/). The President's Service Student Challenge (http://www.cns.gov , Laubach Literacy Action (http://www.laubach.org/home.html), and Literacy Volunteers of America (www.literacyvolunteers.org). For those wanting to use youth as volunteers consult the Family Literacy Foundation for resources. Their Youth Reading Role Models, while geared to youth reading to children could be altered to be geared to youth reading health-related information to adults in various health care settings. (See http://www.read2kids.org/programs.htm)



In recent studies on the effects of using volunteers rather dramatic gains were found. For example, the Literacy Volunteers of America found that on average, student reading scores improve over one grade level with 35-40 hours of tutoring by a trained volunteer. The Literacy Volunteers of America is recognized among many as a very effective training program available for volunteers interested in literacy development.

Community Health Adviser Network Program was created by the Center for Sustainable Health Outreach in Hattiesburg, Mississippi. This center is a collaboration between the University of Southern Mississippi and the Harrison Institute for Public Law of Georgetown University. A full time, paid facilitator is linked with a network of natural helper volunteers at the neighborhood level. The volunteers receive training and mentoring and then help their neighbors and friends with their health-related needs. The volunteers link with public health services when needed through the facilitator. The volunteers seek to improve individual and community health by identifying perceived health problems, organizing self-help action in their neighborhoods and community areas, linking people in need with available health services and giving advice and assistance to neighbors, friends and families. This network provides the missing catalyst link between public health services and community members, particularly for those with low health literacy. It is a program that is being replicated in several states, including Georgia, Alabama and Mississippi.[11]

National Efforts that Support Local Efforts

World Education works all over the world. In the United Stated two projects are currently promoting health literacy. ***Health Education and Adult Literacy: Breast and Cervical Cancer (HEAL: BCC)*** is a partnership between World Education and the Centers for Disease Control and Prevention. The project builds on the three-year CDC funded Health Education and Adult Literacy (HEAL)

project. HEAL:BCC promotes the spread of information about breast and cervical cancer to women who do not have a high school education. The model supports adult basic education and English for speakers of other languages classes as the location for in-depth health education. Materials and technical supports include a comprehensive curriculum, a center-wide orientation and teacher training, materials for learners, linkages with local health care providers, and on-going support and training. World Education will partner with adult learning centers to pilot the model in three states. Evaluation results will be incorporated before moving on to implementation nationwide.

World Education's ***Health and Literacy Compendium*** project provides a unique resource for both health and literacy educators. This annotated bibliography is designed to help literacy teachers find and use health information and to provide health professionals with literacy information and easy-to-read health materials. It presently contains a collection of over 70 citations to both print and web-based materials. The Compendium itself is available on the web at http://www.worlded.org/us/health/docs/comp/ and is linked to actual materials on-line. The project's greatest potential lies in the dynamic nature of the web document which can be continually updated and expanded. The Health and Literacy Compendium represents a collaborative effort between World Education and the National Institute for Literacy.

Health Literacy Month. This is a grassroots campaign to promote understandable health communication across the world. The first event was held in October 2000. During the month, community leaders across the world were encouraged to raise awareness of health literacy in their own communities. This event is expected to grow each year. More resources and lessons learned will be available for local community leaders to draw on. If you are interested in hosting a Health Literacy Month in your community contact Helen Osborn at Health Literacy Consulting to get connected with the latest resources and information available. (Helen@healthliteracy.com or see http://www.prenataled.com/ for suggestions on how to organize such an event in your community.)

The National Alliance of Urban Literacy Coalitions address literacy needs in more than 30 major metropolitan areas across the United States. The Coalition represents thousands of literacy service providers in workplace, family and community-based settings and encourages system-wide cooperation. For those wanting to start a coalition, refer to their site for further help at http://www.naulc.org .

Verizon sponsors literacy Champions. It is a public awareness campaign strategy. This strategy could be applied to all aspects of literacy, including health literacy efforts. Verizon partners with local celebrities in communities to connect literacy to a familiar face, bring attention to this critical issue and raise awareness and funding for the cause. Verizon promotes literacy awareness through a media campaign that includes posters in Verizon stores, bill inserts, calling cards and

newspaper inserts, as well as marketing activities and community literacy-awareness events. See http://www.gtereads.com/champions/default.asp for more details. Starting a health literacy champions effort is a possibility.

Early Start, Even Start, Head Start efforts are beginning to recognize the importance of health literacy learning opportunities for adults involved in their programs. Home visitors are encouraged to add health literacy learning events as part of the home visit. Child care providers and educators are encouraged to add health literacy learning experiences for children and their parents. Head Start and Early Start providers are encouraged to add health services, and hereby add health literacy learning opportunities to their efforts. (See http://www.ed.gov/offices/OESE/CEP/programs.html#prog3 for further description of Even Start efforts. See http://www.acf.dhhs.gov/programs/hsb for Head Start program efforts. See the National Center on Family Literacy for involvement of these national programs related to health and family literacy http://www.famlit.org).

Private Health Provider Settings

Reach Out and Read. This is a pediatric clinic-based literacy program that seeks to make books and literacy "as common as part of pediatric primary care as immunizations." Volunteer opportunities include reading to children in the waiting room and organizing a book drive. The program currently is in 50 states, including South Carolina. It serves annually 1.3 million kids and has distributed annually over 2.5 million books to families. They have trained over 10,000 pediatricians and nurse practitioners. Visit their web site at http://www.reachoutandread.org The aim of this program in most places is to develop parents' general literacy skills. A few places also are sensitive to providing health literacy learning experiences as well.

An example of a nonprofit pediatric clinic model is The Infant Welfare Society of Chicago (Reviewed above). The **Greenwood Community Children's Center in Greenwood** South Carolina is another example providing similar services.

Hospitals increasingly understand their role in preventive health care. Through their volunteer system they are enhancing their services to support adults who have trouble reading, understanding health instructions, and need a listening ear to figure out what to do given their complex medical conditions. Some have expanded their healthy living programs. Health literacy efforts could be an additional component to such programs.

The hospital auxiliary units are a great place to begin health literacy initiatives. Auxiliary members could be trained to help low literate adults read and understand medical consent forms, medical instructions and medicine labels, for starters.

> *"My daughter was asked to translate, in high school Spanish, the procedure for a kidney transplant to a young Spanish-speaking woman whose surgery was due the next day. I found it hard to believe that a hospital so near to us (a major Southern urban center) would not be able to find a qualified Spanish-speaking interpreter at any time of the day. "*

International Efforts that Support Local Efforts

The University of Pennsylvania's School of Education hosts the International Literacy Institute. This institute is the link between the national literacy system's efforts and the international efforts done through the United Nations and OECD's Center for Educational Research and Innovation (CERI). This Institute has summer literacy training programs, hosts regional forums and engages in a variety of research and development projects. Their emphasis is on professional development of literacy providers, including health literacy providers. See http://www.ncal.literacy.upenn.edu/

Sometimes looking at what is being done around the world is a good way to stimulate creative thinking at home. Readers are encouraged to discover what the **United Nation's World Health Organization** is doing on health literacy. You can access their work through the University of Pennsylvania's web site given above.

Models for Increasing Readability and Understandability of Health Messages

Maine's Health Literacy Center at the University of New England specializes in helping professionals learn to plan and create attention-getting communications that are clear and simple. They have a full service package to help health organization's re-do their written communications and review all oral instructions. They have assisted national health agencies, insurance companies, community health organizations, and private industry and health education professionals. They offer a summer institute each year that is a highly recognized program. Visit their site at http://www.une.edu/com/othrdept/hlit/index.htm . It provides a model for South Carolina to follow in having a source for private providers to use to make sure that the written and oral instructions and health education materials are being understood by all adults—those who are literate and those who have low reading and comprehension skills.

Canada's "plain language" movement in health care is changing communications between patients and professionals. The leaders believe that simple instructions and easy-to-read health information will help to improve health care in Canada. A well-organized movement to foster plain language in healthcare materials is under way which emphasizes short, simple sentences with common

words and practical information. The Canadian Public Health Association has sponsored the National Literacy and Health Program. This program is a working partnership of 26 national health associations to raise awareness about literacy and health. They have found that materials should cover only 3 to 5 points, use simple graphics and techniques, such as bullet formatting and bold type, and use common words instead of technical terms. The program has developed an information kit for providers so that they can develop plain language materials. See http://www.hsph.harvard.edu/healthliteracy and http://www.sabes.org/f04resou.htm and the Canadian Public Health Associations web sit for resources on plain language initiative http://www.nlhp.cpha.ca/biblio.htm .

Higher Education Models

South Carolina currently lacks adequate higher education resources and supports to meet the needs of literacy providers. The situation seems to be worsening rather than getting better. State and community leaders have much to do to build an effective higher education system so that professional development and technical assistance needs are met. There are higher education models in other states that model possibilities for South Carolina's higher education system and its role in improving health literacy skills of its residents.

The following colleges and universities are within a 60-mile radius of most towns in Chester and Lancaster County. At least part of the answer to the low literacy rates in these two counties involves getting higher education focused on literacy development in general and health literacy as it relates to this report's focus. Faculty and students from the following colleges and universities are encouraged to join community leaders in creating a strong literacy education system in these two counties. They are Allen University, Benedict College, Coker College, Columbia International University, Columbia College, Lutheran Southern Seminary, Morris College, Palmer College, the University of South Carolina, The University of South Carolina Lancaster, the University of South Carolina Union, Winthrop University, and Newberry College.

A few models of what higher education is doing elsewhere are given to stimulate thinking about what could be done in Lancaster and Chester Counties through higher education involvement with county literacy providers.

Georgia State University, Center for the Study of Adult Literacy has led the way in developing measurement tools to measure rates of health literacy. Their staff, working with faculty from Emory University developed the most widely used health literacy measurement instrument reviewed in a previous section of this report. They are particularly interested currently in women and health literacy issues and research. See http://www.education.gsu.edu/csal/

The University of Maine's Health Literacy Center is a good example of one institution that has consciously organized its public service functions so that private health organizations have help available to take a look at their materials and communication systems so that they promote effective health literacy standards.

Harvard University's School of Public Health is the home of the National Center for the Study of Adult Learning and Literacy that is connected with the national literacy system. They have created a practitioner research network that is a model for what could be done within South Carolina. They link practitioners with researchers for information sharing purposes. They help identify practitioner sites that would be willing to be research sites. They keep abreast of what various researchers are doing and bring practitioners together with researchers to discuss topics of common interest. They share results of research in useful ways. This center is also a model of the kinds of studies that could be done in South Carolina so that the outcomes and impacts of health literacy education in communities throughout South Carolina is better understood. See http://gseweb.harvard.edu/~ncsall/

Brown University has developed a model web-based online resource for literacy educators. Its is called the Knowledge Loom. (See http://www.knowledgeloom.org) It presents principles of best practice for teaching and learning in various subject areas, including literacy. The early literacy best practices section is already developed. During 2001 and 2002 the adolescent and adult literacy best practices will also be online. The way in which this site is structured is a model from which other higher education units could learn. (See http://www.lab.brown.edu/public/literacy/implementq.shtml)

The Student Coalition for Action in Literacy Education (SCALE) at the University of North Carolina at Chapel Hill is a model of what a network of college students, adult learners, administrators, literacy practitioners and community partners can do to implement and support participatory education and social change work in campus-based literacy programs. It also hosts a consortium of campus-based literacy programs implementing and expanding a service-learning initiative related to literacy. Each network partner conducts a seminar and initiates an action project. This consortium involves colleges in Georgia, Ohio, Minnesota, South Carolina (Benedict College), New York, Washington, D.C., Pennsylvania, as well as North Carolina. (http://www.unc.edu/depts/scale/mission.html)

Several other universities are affiliated with the LINC system and are strategically helping to create parts of the literacy system as described in the National Literacy Act. A similar higher education system is needed in South Carolina to support the technical centers now being developed by the South Carolina Literacy Resource Center and local literacy providers.

What Can We Learn From These Efforts?

About The Need for Collaboration

- The most comprehensive impact on health literacy is done through the formation of a partnership of public and private agencies working together, sharing resources, and each improving their own health literacy services, information and communication practices.

About Who Is Responsible For Ensuring A Health Literate Adult Population

- Becoming a health literate county is just as much the responsibility of the health provider as it is the health consumer.

- Higher education institutions have a vital role to play in supporting local efforts and helping state, county and community leaders meet the challenges described elsewhere in this report. Professional development of health literacy providers is needed throughout the United States, including South Carolina. We need to advance our understanding of the impact of health literacy and how best to increase the rate of health literacy. A strong, practical research program is needed in South Carolina on literacy in general and on health literacy, in particular. Higher education faculty members must be linked in intentional ways with literacy providers in order to increase literacy rates. Students as well as faculty have important roles to play in providing literacy services in low resourced communities.

About The Need for Integration

- Adult education programs can integrate health literacy learning experiences into all areas of their curriculum and connect to other initiatives such as family literacy, adult basic skills education (ABE) , ESOL classes, worker literacy and citizen literacy efforts.

- Family literacy and health literacy efforts go together very well. Think of ways to integrate health literacy into programs offered routinely by state government and the nonprofit sector in your area. There is a particularly good fit with family literacy efforts. Find ways to integrate health literacy into state and county departments of health, education, and social service family-focused programs. For example, many of the public health departments, including those in South Carolina promote the use of the *Parent and Child Together* Time (PACT). This is a

> *"I'm Chinese speaking. I went to a major hospital nearby for treatment and was terrified to find not one person who could communicate with me. I knew no English. It was the most frightening time of my life."*

necessary component of effective family literacy programs. The SABES program in Massachusetts promotes incorporating appropriate health activities into the PACT program. Discussions about appropriate health activities (e.g. importance of washing hands or eating nutritious meals), healthy eating habits, exercising tips, how best to talk with the pediatrician or where to access medical help at reasonable costs can be incorporated easily into PACT program activities. *Home visitor programs* done by the Department of Education, the Department of Health and Environmental Control, and Department of Social Services or by various nonprofits can easily incorporate health literacy teaching and learning efforts into a home visit. In some places home visitors bring backpacks of health related activities to do as a family (e.g. home safety; street safety, dealing with conflict; communicating how one feels physically). *Early childhood development programs*, such as those launched under the First Steps initiative, can promote health literacy in their efforts. *Adult education programs* in every county can be encouraged to incorporate health content for reading, writing, speaking, listening, and problem solving activities per learner choice and interest. Special health related projects might form the basis of learning literacy skills for adults. So the health literacy initiative need not be seen as a stand-alone effort in communities.

- Those working in health clinics and pediatric offices that have incorporated health literacy learning opportunities through their practices have learned the following things:[12]

- It helps to personalize health information by putting the patient's name on it.
- It helps to review the content with the patient to see how much they comprehend messages and to allow opportunities to re-enforce important information and instructions.

- It helps to highlight or circle the important information.
- It helps to ask questions that require the patient to find information on the paper.
- It helps to repeat the most important points as needed.
- It helps, if you believe the patient can't read, and you know the information is vital, to audio tape the highlights for them. Some give inexpensive tape recorders to their patients for this purpose.

• Adequate understandings of health literacy skills should shape the way health promotion happens. It should affect what is said, how it is said, what kinds of communication processes are used. Health literacy education is not the same as health promotion education. In order for a health promoter to truly begin health literacy efforts, they must consciously be thinking about health literacy and basic literacy skill development. In addition, an adequate understanding of health literacy should make health promoters understand that given the right set of circumstances anyone's literacy skills may be inadequate. This understanding should re-shape health settings so that they are active learning settings and provide every adult with resources to make learning possible and understandable so that wise health behavior choices can be made.

> *"We went to get help for my dad. I tried the best I could to translate what the nurses and doctors were saying. I'm good in English. You know, the kind we speak at school and around the neighborhood. But these doctors and nurses were using words and phrases I didn't know how to translate. In some cases there were no words for what they were saying in our language. I tried the best I could, but really made mistakes. Then we got scolded for not following directions when my dad got worse. Why can't they communicate in plain English? That's all we asked. They should know their field well enough to communicate it clearly to those of us not schooled in their lingo."*

• Health literacy initiatives need to pay attention to the literacy levels of learners and where they get health information.

About the Need for A Clearly Defined Leader

• The Massachusetts' initiative teaches us that communities need resources and technical assistance to get health literacy efforts well incorporated into community educational opportunities. They created a health and literacy liaison system. Someone has to intentionally lead the effort, even though partnerships are needed.

About Costs

- The cost of integrating health literacy efforts into community-based organizations is actually fairly reasonable. On average, the cost is approximately $22,000 per year for those wishing to follow Massachusetts' lead. This includes hiring five health facilitators at 5 hours per week for 42 weeks at $25 an hour; paying a health team of five $10 an hour for four hours of work per week for 42 weeks; and allowing $2000 for materials and software, approximately $300 for travel and $4200 for curriculum development. During the initial phase when the health team needs mentoring an addition $1200 is reserved to train the team.

This 5-member health team becomes responsible for doing health fairs, gathering resources, preparing materials and events, developing collaborations with local health and allied organizations such as family centers, human service nonprofits, and churches. A complete job description for this model is found on the SABES web site. It might be a good place to start before resources are appropriated for a larger initiative or as a compliment for a staff lead initiative such as is the case in Massachusetts.

About Cultural Compatibility

- Communities with low levels of functional literacy need to generate their own informed health messages that best fit their local situation.

- With ESOL learners health messages cannot just be translated from English into their native language but need to be developed with the cultural context in mind. Often this translation is best done by involving local ESOL instructors who know the area and particular cultural beliefs and practices of local ESOL learners.

The next section of this report identifies the components of a successful health literacy initiative.

What Will Help Us Be Successful?

This section of the report identifies a variety of ways to get started. While leaders are encouraged to think about a collaborative effort to build a strong health literacy system, we encourage leaders to also think about what they can do to improve their individual efforts.

Leaders can do the following things in order to insure a successful health literacy initiative. They can:

- ground health literacy issues within their specific context.
- envision what an effective health literacy system would look like given their specific context.
- identify, based on their vision, what outcomes they intend to reach with their efforts.
- create efforts that will best insure they reach their intended outcomes.
- find partners willing to share resources and work load.
- use effective adult teaching and learning principles to guide their educational and communication behaviors.
- design and implement an evaluation program.
- communicate through a mass communication campaign what health literacy is all about and its importance to individuals, families and the economy.

A few pointers on each of these tasks are given below.

Start by Determining Your Community's Health Literacy Issues in Context

In order to tackle issues one must ground them. Grounding an issue means to describe and address the features of a specific context or situation that make it an issue in order to clarify what is at stake. Otherwise the solutions suggested are typically off base or too general to gain people's attention. No two communities have the same contextual features to their health literacy issues (or any issue for that matter). So it is important to understand the specific features of the health literacy issues in your community and area. Why are so many testing so low? What are health providers doing to improve literacy rates? What are people's values and beliefs about health practices? What is the general population's beliefs about what literacy is and isn't? Who is doing what regarding health literacy?

Two different kinds of community dialogue processes work well in helping community leaders ground health literacy issues. Choose one and conduct an issue framing dialogue process so that you know the specific features and characteristics that must be addressed to effectively tackle health literacy development in your area.

One community dialogue process is the Study Circle Resource Center model. Study circles can have any discussion topic community leaders or members want. Health literacy issues and why health literacy is an issue could be a discussion topic. Study circles are small group, democratic, peer-led discussions. The Study Circle Resource Center has created a variety of support materials and services to help interested groups get started and conduct study circles. See their web site for

guidebooks that can be downloaded. http://www.studycircle.org/ Sometimes the name "study circle" is not an appropriate name to use. For example the Anderson Healthy Partners groups named their effort "neighborhood chats".

Table 3. A Possible Vision Statement of an Effective Health Literacy System in Lancaster and Chester Counties

An information creation and dissemination system. Plain language health materials are available to any adult and professional needing them. Services are accessible to help health professionals assess the readability and understandability of the health information materials they use with their patients. Adults, irrespective of literacy levels, can access health information that is understandable. This information is available through sources they trust. Information is found in many forms (e.g. written, audio, audiovisual, visual, in a variety of languages). It is sensitive to a variety of cultural needs. There is a place where health professionals can go to have their materials checked for readability and understandability. The higher education system within the state is connected with literacy practitioners in the community. Professional enrichment is available. Practical research is done which improves health literacy programs, health professional practice and learner health literacy skills. Information is shared among researchers and practitioners. Adult learners are empowered to be a part of this information, creation, and dissemination system. Elementary, middle and high schools, technical colleges, colleges and universities faculty and students are involved in health literacy service learning projects in every community within both counties.

A coordinated health literacy learning system. Existing learning opportunities include health literacy content in their instructional plans. Educators know and plan their instruction around what the 13 common everyday literacy-related activities are in order to be an effective health consumer and provider. They plan instruction around the four literacy skills sets. They make applications to learners' everyday needs as health consumer and provider. Every learning opportunity present in each community includes health literacy activities as part of its overall learning package. Family and senior centers include health literacy training with their family literacy efforts. Health literacy efforts are found in all the schools, public agency programs, in family and neighborhood center programs and in healthy community efforts. There is a self-learning system, such as the Healthwise movement, that allows adults to learn about health issues when they are ready and want to learn. The learning system is non-stigmatized, easily accessible and reinforced with a formal and informal health advisement system such as the Mississippi community health adviser network initiative.

A health literacy measurement and assessment system. County leaders know their population's health literacy rates. They measure these rates periodically using TOFHLA. They insure that South Carolina is a part of the 2003 National Adult Literacy Survey so that South Carolina has a robust statewide sample and clear picture of its literacy situation. They target services and supports for health literacy education where there is the most need. They assess current health literacy development efforts for the presence and effectiveness of current health literacy education. They measure important indicators that tell whether increasing health literacy rates is having a positive affect on the economic, business, human growth and development outcomes often associated with low health literacy rates.

A formal and informal health decision making advice system. There is a phone number any adult can call anytime to help them make wise decisions about health related issues. Health literacy volunteers are organized at the local level through church networks, through higher education service learning projects, through neighborhood associations and other locally based civic groups. These volunteers are available to any individual in the community to help them problem solve health-related situations. Each household has a *Healthwise* handbook, or other plain language health decision making materials, which helps everyone take charge of health care decisions. Each household can access a Nursewise hotline. Each household can access a health educator who can provide understandable information. Computerize health decision support aids on health topics are available through all the public libraries. There is a health consumer librarian available within the county that helps organize library resources related to health literacy.

A professional health provider learning system. There are opportunities organized for all professional doctors, nurses, and health educators to learn how to speak and write in plain language. On-the-job seminars are offered. On-site coaching is done based on observation of the health professional's interaction with low literate adults.

A second community dialogue process is an issue forum as developed by the National Issue Forums (NIF) network. It is a nationwide network of educational and community organizations that discuss issues of major significance. NIF forums provide a way for citizens to exchange ideas and experiences with one another to make more thoughtful and informed decisions. Typically, a critical issue is identified; for example low health literacy rates and their effects on county or community residents and businesses. Then a non-partisan issue book is written based on local ideas, varying perspectives and options for taking action. Local forums and study circles are conducted using the issue booklet. A community wide forum is conducted to share the results of the forums and study circles and action plans are created. See http://www.nifi.org/ for details. One key distinction of this group's approach is that citizens are asked to think about and consider the value of opposing and alternative perspectives on an issue. This thinking process helps build literacy skills that can contribute to the development of citizen literacy. Notions such as tolerance and cultural diversity can not be developed until people learn to think and appreciate the wisdom found in multiple perspectives.

Visioning: What Are the Components of an Effective Health Literacy System?

Grounding health literacy issues provides part of the information needed to develop an effective vision. A strong vision guides and grounds effective practice. Visions are developed based on participants' understanding of issues, assets and effective practices.

Table 4. Possible Outcomes for A Health Literacy Effort In Lancaster and Chester Counties

Possible Health Literacy System Level Outcome By 2010 there is a coordinated system of health literacy services that connect public and private agencies so that any adult wanting to improve their health literacy skills can do so in a timely, cost effective manner, free from stigma, and in a useable form. A system of health literacy services and supports is available so that all willing individuals are able to achieve their health learning, health maintenance and health provider goals.
Health Consumer and Provider Learner Outcomes Health consumers and providers in Lancaster and Chester County can obtain, interpret, and understand basic health information and services and have the competence to use such information and services in health-enhancing ways.[14] They obtain and manage information by proficiently using the 4 *Equipped for the Future* literacy skills sets across 13 everyday health literacy related activities.

Massachusetts models what an effective health literacy system might look like. While it is suggested that community leaders develop there own vision for what an effective health literacy system would look like in both Lancaster and Chester counties, one possible vision is included here. It draws from Massachusetts' work. An effective health literacy system in Lancaster and Chester counties might function as described in Table 3.

The functions identified in Table 3 are the system components found most often throughout the United States. Leaders in Lancaster and Chester counties may want to use the sample vision statement to begin thinking about what kind of health literacy system they want, what kinds of partnerships are needed, and who will do what on behalf of the partnerships. Other system components might be needed based on discussions. Use the model program and resource sections of this report to identify and draw on resources that might help you develop health literacy system components.

Determine Outcomes Based on Vision

Once a vision is created, then outcomes can be developed for each part of the vision. Two different levels of outcomes might be created. Health literacy *system outcomes* and *program level outcomes*. The system level outcomes state positively what various organizations are doing to provide health literacy services to learners in an improved situation. The program level outcomes express what learning outcomes in adults are desired in an improved situation.

At the learner level, the National Institute for Literacy has defined the primary literacy outcomes sought for the roles of worker, parent and citizen. The *Equipped for the Future* standards report provides learning objectives related to each outcome statement.[13] The Joint Committee on National Health Education standards form the basis for the health literacy consumer and provider outcome. At the systems level, the National Literacy Summit provides the basis for a system-wide outcome statement. Using these sources as a base, possible system-wide and learner level outcomes for a health literacy initiative are given in Table 4.

The next section begins to address competency level objectives for health literacy learning opportunities. *The learning objectives need to be based on enhancing competence in performing enduring adult everyday activities related to the role of health provider and consumer.*

Frame learning outcomes around 13 core health consumer and provider literacy-related everyday activities.[15] What daily activities do people do related to being a consumer and provider of health care? What do they do to become healthy and maintain health? The National Institute for Literacy identified 13 core activities that are common to all the major roles adults tend to play. Three roles (parent, worker, and citizen) were emphasized in the EFF standards. These same activities are also common to adults who personally maintain their health and are

consumers and providers of health care. These 13 activities are integrative cognitive, social, and behavioral processes that endure over time, even in the face of changes in technology, health care system changes, work processes, and societal demands.

Creating learning experiences around these 13 activities is central to health literacy program development. Creating health care environments in which people can gain these skills is at the heart of creating an effective health literacy system. *Health literacy learning, advisement and tutoring efforts address one or more of the skill-based, health consumer and provider role-related activities found in Table 2* of this report. These 13 activities are part of consuming health information and services effectively and providing effective health care for one's self and others.

Back to Addressing Literacy Skill Development within the Framework of Health Literacy Education. There may be a tendency for some professionals to start calling everything health literacy education when, in fact, it is not. One can not address health literacy education without developing instruction on basic literacy skill development. Healthy living is the content of health literacy education. The development of literacy skills so that people can obtain, interpret and understand basic health information and services and have the competence to use such information and services in health-enhancing ways is at the heart of health literacy education.

As mentioned in the first section of this report, adults need four fundamental kinds of literacy skills to draw from in order to carry out the key activities that are central to their primary role as health consumer and provider. They need communication, decision-making, interpersonal and lifelong learning literacy skills. In the past, literacy was often thought of as only those skills found in the first category: communication skills. Some even tend to think of literacy only as being able to read and write. See Table 1 for a reminder of

what these 4 basic literacy skills sets are. *In order to have an effective health literacy effort, leaders must consciously address the development of one or more of these four literacy skill areas.*[16]

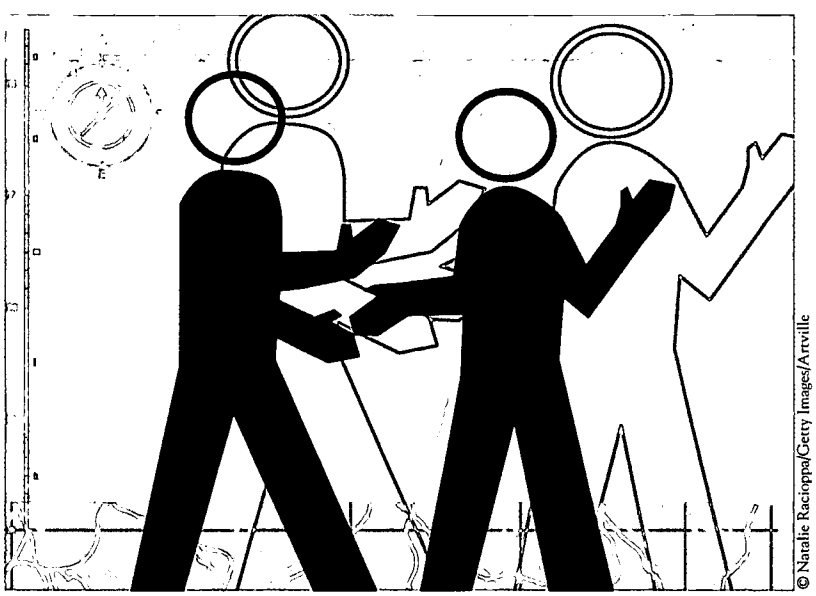
In summary, effective health literacy efforts identify system level changes needed and health literacy learning outcomes. An evaluation program cannot be designed until intended outcomes are known. Effective efforts start by articulating outcomes and then choosing strategies that have the best possible chance of reaching those outcomes. This may sound logical, but is rarely done. People sometimes get caught up in implementing a favorite solution or program without clarifying what outcomes are sought and why. Declare health literacy outcomes first and then determine what to do to insure that those outcomes are obtained.

What outcomes should be achieved? Effective outcome statements are linked conceptually to visions for improvement. They are based on trying to improve the basic literacy skills mentioned in Table 1 and the 13 common role related behavior sets mentioned in Table 2. The outcomes should also be patterned after effective health literacy efforts elsewhere. In other words, draw on your own vision for improvement based on your understanding of your particular context, on nationally recognized practices and the thoughtful work of scholars and practitioners across the U.S. Much of this wisdom is summarized in this report.

Once outcomes are identified, selecting appropriate ways to measure these outcomes becomes possible.

Building Necessary Partnerships

An effective way to insure a health literate population that can take charge of health decisions and reduce costs is to form a partnership. Leaders from limited-resource communities particularly may need partnerships so assets can be leveraged and enhanced. Partners may include leaders from hospitals, businesses, insurance companies, local governments, physicians, nurses, health educators, librarians and nonprofit organization leaders who care about the importance of having a health literate population.



A partnership functions best when every partner has a responsibility and knows what is expected of them. Each partner has the resources necessary to accomplish their responsibilities. Local resources are leveraged so that those who are willing to lead have the resources necessary to do a good job on behalf of the partners. The partnership has a coordinating

center of operation. In many places this coordinating center is a health district office, a private nonprofit formed through healthy community deliberations, or a literacy council. Partnerships take hard work to form and even harder work to keep going. Therefore good leadership is required in order to build a strong health literacy system.[17] Effective leadership is intentional, visionary, and continually communicates and leads.

Use Effective Adult Teaching and Learning Principles to Guide Instructional Development and Communication Practices

Sometimes teaching behaviors are shaped by what was seen in school settings. For low literate adults, (as well as children and youth) schooling models of teaching are not valued. While some of the model efforts described elsewhere in this report are more schooling oriented in approach, we encourage leaders (e.g. doctors, nurses, health educators, adult educators, school teachers, family center program officers, family members, friends, volunteers) to think about effective moments when they are teachers. These principles are for you. Traditional schooling approaches to teaching adults do not tend to work well, particularly with level 1 and 2 literate adults. Think about how adults learn and therefore how to effectively teach them by framing your teaching around what they do in their role as health consumer and provider. *Effective adult educators of health literacy efforts do the following things. A fuller description of these educational principles is found in the Appendix.*

1. Adult health literacy educators link new literacy learning to an adult's prior health consumer experience.

2. They help adults meet specific health literacy learning goals related to their own health literacy needs.

3. They help adults meet specific health literacy learning goals related to their role as educator of their children's and other family member's health literacy needs.

4. Their health literacy instruction is experientially based.

5. They are able to assess various learning styles of adults and communicate new health literacy information and skills to them in ways they understand it.

6. Their literacy learning experiences are contextual.

7. They communicate effectively with adults who have differing ways in which they think about and take action on health consumer situations.

8. They are able to work in a variety of health consumer and provider settings with a variety of different types of community leaders.

9. They effectively involve adults in planning their own health literacy learning.

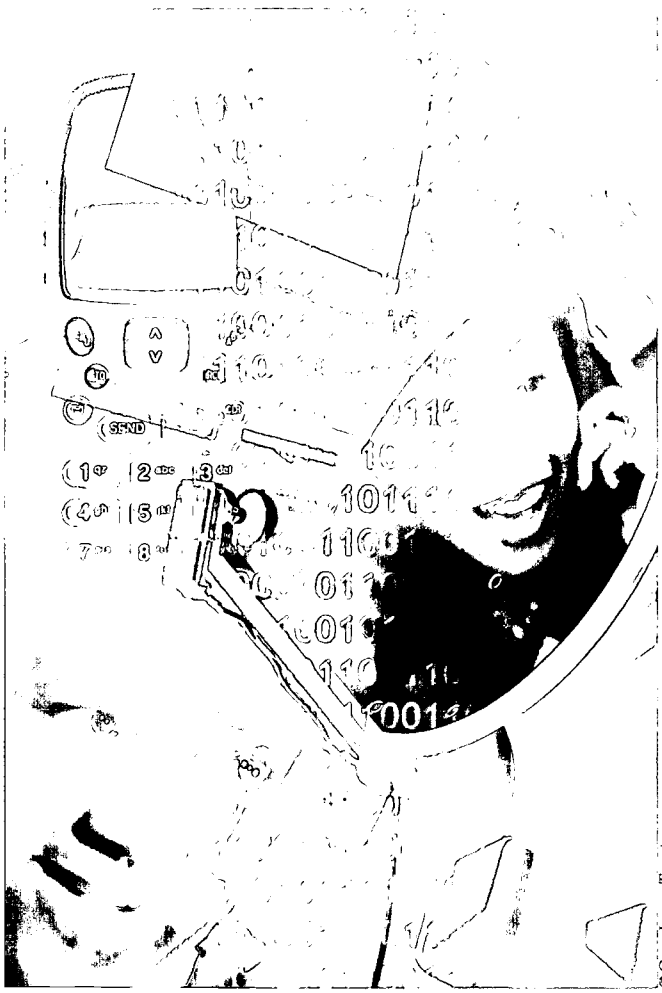
10. They market their health literacy learning offerings effectively.

11. They understand that retention of adults in health literacy programs is a problem and act accordingly.

12. They reward adults who have successfully completed a health literacy learning program or accomplished correctly a health maintenance or decision-making task.

Applying these principles is hard work. We are all health literacy educators either formally or informally. So these principles are for everyone.

It takes thinking and acting outside the "schooling" instructional box. In situations were programs are offered, recruitment and retention rates often directly correlate to how successful one is in applying these principles of teaching and communicating. Reaching learning outcomes such as those mentioned elsewhere in this report are conditioned on effectively using these principles.



© Getty Images/Eyewire

Design and Implement A Health Literacy Evaluation Program

Evaluation cannot occur unless there are clearly articulated outcomes and related literacy development strategies present. These should be defined early in the development effort. In addition, a clear profile of targeted learners should be developed. Strategies employed should fit logically with the outcomes sought. Strategies employed should be based on what is known to work. Once the audience is specified, and outcomes and strategies are determined, then the needed information is available to guide the evaluation design.

A whole book could be written on evaluation.[18] That isn't the purpose of this report. Involve community members who know how to do evaluation in your community's health literacy initiative development. Engage them during the planning process because, if you answer the questions they need for the evaluation design, you will have what is needed to develop the initiative in a sound manner.

Build A Health Literacy Public Awareness Campaign

The final section on how to get started deals with building the public's awareness of health literacy issues and system development challenges. In the model program section of this report the Verizon Literacy Champions model is given. Sprint also has a program. The Success by Six initiatives provides another useful model to examine.

Creating awareness of the issues is part of the process of helping all residents begin to increase their own competence. Resources will be more easily harnessed if word gets out about what is at stake. An effective public awareness campaign is a necessary component to a functioning health literacy system. The more the public addresses local specifics of health literacy the better chances of securing attention and action.

What Health Literacy Resources Are Available?

Many resources were identified throughout this report. Some additional key resources are cited below. For those reading the web version of this report, the blue underlined text is linked to the web site for convenience. By going to these web sites an entire resource collection on health literacy is available to you. This listing is selective, but by accessing these sites other resource agencies can be identified and their resources accessed.

National Organization Resources

The key national organizations that promote literacy development in general and also related to health literacy are reviewed below.

National Institute for Literacy
800 Connecticut Avenue, N.W.
Washington, DC 20202-7560
Phone: (202) 632-1500
http://www.nifl.gov/

NIFL was created as a result of the National Literacy Act. It is the national hub through which the literacy system in the United States is to be built. NIFL is the primary source to turn to for finding out about literacy organizations and initiatives at the state and national level. NIFL's web site includes an online directory of literacy resources across the nation. A complete description of the regional resource center system is also there. These regional centers are called LINCS (Literacy Information and Communication System). Use the ***LINCS*** connections to access region- and state-specific resources. NIFL's Eastern LINCS web site is home to a special collection of literacy and health information.

World Education
Health and Literacy Initiative
44 Farnsworth Street
Boston, MA 02111-1211
Phone: (617) 482-9485
Fax: (617) 482-0617
http://www.worlded.org

The Eastern LINCS health literacy emphasis was developed by World Education. World Education is known for excellence in its work all over the globe with low literate communities. The Health and Literacy Initiative of the Eastern LINCS has developed a Health Compendium. The Health Compendium is a special web-based collection of health and literacy resources. World Education, through various literacy projects, provides technical assistance with materials assessment and development and participatory health education program development. They are currently providing technical assistance to ABE and ESOL programs that are integrating health into existing curricula; implementing the HEAL:BCC Project, a national demonstration project that brings breast and cervical cancer information into literacy and high school equivalency programs. They also coordinate the Massachusetts Health Team, a collaboration of health educators and literacy practitioners.

The Midwest LINCS
Kent State University
Access site through the NIFL web site
http://www.nifl.gov/

The Midwest LINCS has a helpful guide to establish program quality indicators (called the Indicators of Program Quality Resource Guide). While it is written to address program quality indicators for literacy programs in general, it will be useful to those groups wishing to create a health literacy program. With slight modifications, it will help form a good basis for a rigorous program evaluation.

U.S. Department of Education
Office of Vocational and Adult Education (OVAE)
Division of Adult Education and Literacy
400 Maryland Avenue, SW
Washington, DC 20202-7240
Fax: (202) 205-8973
http://www.ed.gov/offices/OVAE/AdultEd/

The Division of Adult Education and Literacy, in the Office of Vocational and Adult Education (OVAE), administers the Adult Education and Family Literacy

Act, Title II of the Workforce Investment Act of 1998 (Public Law 105-220). The Adult Education and Family Literacy Act is the Department's major program that supports and promotes services to adults who are educationally disadvantaged. The Division maintains cooperative and consultative relations with Federal, State, and local agencies that provide basic skills services. It maintains a Clearinghouse that offers national information resources on issues and trends in adult education and literacy, publishes a newsletter, the *A.L.L. Points Bulletin*, and reports on promising practices in adult education. It has fact sheets and online resources related to health literacy. Consulting these fact sheets will allow the reader to easily access most of the resources available online. Their web site contains links to most of the major web sites connected with literacy education. Readers are encouraged to start there to quickly link to all major sites. (Click on Related Links.)

National Center for the Study of Adult Learning and Literacy (NCSALL)
Health and Literacy Studies
Harvard School of Public Health
Department of Health and Social Behavior
677 Huntington Avenue
Boston, MA 02115-6096
http://www.hsph.harvard.edu/healthliteracy/

"I'm 78 years old and have worked most of my life. I value my independence. I probably should go into a nursing home but I don't have the money and don't want to be so controlled. I was diagnosed with congestive heart failure, coronary artery disease with angina, hypertension, diabetes, and arthritis some years ago. Over the last several years I have been in and out of the hospital several times. "

This site is designed for professionals in health and education who are interested in the issue of health literacy. It contains materials you may find useful for your work:

- A PowerPoint overview of health literacy
- A video entitled *In Plain Language*
- A literature review and annotated bibliography of published research in medicine and public health
- Research reports from the Health Literacy Study Group
- Innovative materials
- Health Literacy and Health Communication Curricula
- Links to a variety of web sites related to health and to literacy

For those interested in starting research projects this site will also be particularly helpful and instructive.

The National Center for Family Literacy
Research: Literacy Facts and Figures
http://famlit.org/research/research.html

This is the best compendium of statistical indicators and research findings that relate to literacy as well as other educational and social conditions that were found. It covers statistics related to the scope of adult literacy in the U.S.; literacy and welfare; literacy and crime; education and voting behavior; literacy, families and children; schools, teachers and learning; reading and the home; children learning to read: success vs. failure; television and literacy; homework; absence from school; parental involvement; fatherhood; the impact of welfare reform; technology, early childhood intervention; and research reports.

Health Promotion Council of Southeastern Pennsylvania
311 South Juniper Street, Suite 308
Philadelphia, PA 19107-5803
Phone: (215) 546-1276
Fax: (215) 545-1395
http://www.hpcpa.org/

The Health Promotion Council promotes health to those at greatest risk through publications and training. They have a multi-cultural, multi-lingual staff and an emphasis on culturally competent health communications. Their pamphlets and audiovisuals for African Americans, Latinos, and Asians, written at or below a sixth grade reading level, currently cover blood pressure, diabetes, smoking, stress, nutrition, and use of the health care system. The Council has materials in Spanish, Cambodian, Chinese, and Vietnamese. They have a seven-to-eight-week training and curriculum for community-based hypertension and diabetes control, offered in both Spanish and English. They have a Community Healthcare Interpreter Training project which provides high quality and standardized training program for interpreters who work in health care settings in order to improve the quality of health care for limited English speaking consumers. They have a health literacy technical assistance service to help health care professionals learn to communicate effectively with low literate consumers.

National Assessment for Adult Literacy
National Center for Educational Statistics
Washington DC
http://nces.ed.gov/nall/defining.defining.asp

This site will give you the facts related to which states participated in the 1992 national literacy survey. S.C. was not one of them. Each state had to pay for its involvement and S.C. did not do so. The site contains definitions of each kind of literacy skills tested and definitions of the levels for each of the three areas tested (prose, document, and quantitative literacy levels). It provides samples of test items.

This site will be useful to those who need to educate boards, staff and community leaders about literacy issues and skills. It will help make sense out of what it means to have 56% and 60% of the adult populations in Lancaster and Chester Counties respectively at a level one and two literacy proficiency.

Alpha Plus Centre
21 Park Road
Toronto, Ontario M4W 2N1 CANADA
Phone: (416) 397-5900
Fax: (416) 397-5915
http://www.alphaont.ca

The Alpha Plus Center provides resources for adult learning. The web site houses the online catalog of the Center's adult literacy library that includes a large selection of health education materials. While only citations are available online, the Center is willing to lend publications, for a fee. They distribute a "mini-bibliography" of information about health and literacy. They provide information for the Anglophone, Francophone, Native, and Deaf communities of Canada.

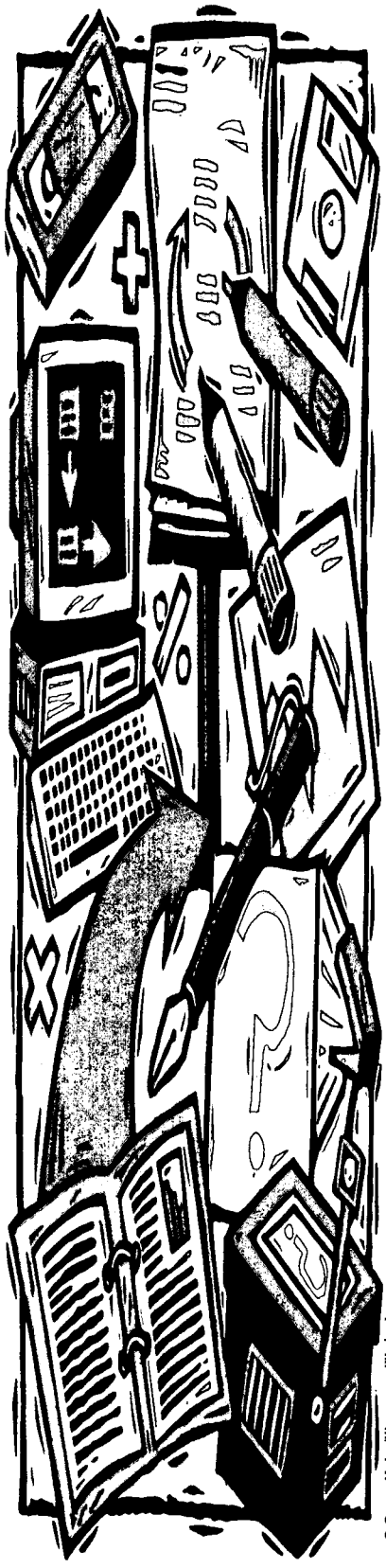
American Association for Advancement of Science

1200 New York Avenue, N.W.
Washington, DC 20005-3920
Phone: (800) 229-7809
Fax: (202) 371-9849
http://www.aaas.org

The AAAS is home to the Science + Literacy for Health program which aims to help people understand concepts in biology and health. Click on Science and Education. They have produced a number of short readers on health and science topics at a GED level. Some of these are now available online. See their web site to view *Your Genes, Your Choices* about the Human Genome Project.

Canadian Public Health Association
National Literacy and Health Program

I now live with my oldest daughter and her children. I have my good days and my really bad days now. When I'm o.k. I can help around the house doing chores and baby-sit grandchildren. I can take brief walks. But on my bad days, I need attention from a healthcare team. I'm on a modified diet and must restrict my intake of sweets and salted foods. I take six different kinds of medications. It's sometimes hard to keep it all straight. I forget which I have to take when and for what. I am suppose to monitor how I feel and record it. I'm suppose to let my health care provider know when there are significant changes in how I feel. I have a number of doctor's appointments and frequently have to go through lots of tests. I sometimes forget my appointments; there are so many of them. Sometimes I forget what I'm support to prepare for and do the wrong preparation. My vision is getting worse and I can't always read the little print on the instruction they give me to follow. The kids are not always around to tell me what they say. All this makes me really nervous."



1565 Carling, Suite 400
Ottawa, Ontario K1Z 8R1 CANADA
Phone: (613) 725-3769
Fax: (613) 725-9826
E-mail: hrc/cds@chpa.ca
http://www.nlhp.cpha.ca

The National Literacy and Health Program of the Canadian Public Health Association promotes awareness among health professionals of the links between literacy and health. It produces an information kit on Literacy and Health for Life that covers the scope of literacy issues in Canada; links between literacy status and health status; and plain language philosophy and techniques. By the end of 1999, they plan to publish the North American Plain Language Health Information Resource List. Their *Easy Does It* health communication training package is very good. There is a training manual, CD-ROM plain language game, and a video. A companion to *Easy Does It* is a guide with practical strategies for working with low-literacy seniors. *Easy Does It* is frequently referred to on all health literacy web sites.

Laubach Literacy Action (LLA)
1320 Jamesville Avenue
Box 131
Syracuse, New York 13210-0131
Phone: 315-442-9121
Fax: 315-422-6369
http://www.laubach.org/home.html
For information only: 1-800-Laubach

LLA is a leading nonprofit organization established in 1955 to train volunteer tutors to help adults and older youth improve their lives and communities by learning to read, write, do math and learn problem solving skills. It is now gone international and is in more than 36 countries. They have a very extensive publishing house, called Grass Roots Press, with materials very useful to those involved in all aspects of literacy training—health, family, workforce, and citizenship. The web site for the press is http://www.literacyservices.com/healthandlit.htm

Literacy Volunteers of America
635 James Street
Syracuse, New York 13214
http://www.literacyvolunteers.org

LVA is a national nonprofit founded to combat problems of adult literacy in America. Its primary premise is that well-trained and supported volunteers can be effective tutors of adults. It is currently under negotiation with Laubach Literacy Action and may well emerge with that group.

Institute for the Study of Adult Literacy
Penn State University
102 Rackley Building
University Park, PA 16802-3202
Phone: (814) 863-3777
Fax: (814) 863-6108
isal@psu.edu

The Institute for the Study of Adult Literacy has a number of ongoing, collaborative, health-related research and curriculum development projects. Examples include working with Howard University on CARDES (CARdiovascular Dietary Education System), a project to develop nutrition educational materials for limited-literacy, urban African Americans; working with the American Cancer Society, the Pittsburgh Cancer Institute, and the Cooperative Extension Service on the Northern Appalachian Leadership Initiative on Cancer; and working with the National Health and Education Consortium on developing Rosalie's Neighborhood, a curriculum that is part of a parent information project on health.

Office of Minority Health
P.O. Box 37337
Washington, DC 20013-773
Phone: (800) 444-6472
http://www.omhrc.gov

The Office of Minority Health provides print and online information and resource contacts about minority health issues. The Office's online database of organizations, programs, and documents includes contact information. The Office's resource persons network sets up health professional volunteers to provide technical assistance to community-based organizations regarding minority health issues. The newsletters are distributed free to interested parties.

Health Literacy Consulting
31 Highland Street Suite 201
Natick, MA 01760
http://www.healthliteracy.com

This consulting firm is consider a national leader in assisting health professionals develop clear communication and written material for low literate populations. They also conduct training sessions for health professionals on a variety of health literacy topics, as well as consult with healthcare organizations and professionals.

AMC Cancer Research Center
1600 Pierce Street
Denver, CO 80214
Phone: (303) 239-3405
http://www.amc.org

The AMC Cancer Research Center is one of the founding member organizations of the National Work Group on Cancer and Literacy. People at the Center have created materials appropriate for use in adult literacy classes about breast and cervical cancer early detection. There is hope that the materials will be funded for national distribution in the near future. The Research Center has also created how-to materials about health and literacy agency collaborations, focus groups for planning cancer education programs, and more.

Regional Resources

System for Adult Basic Education Support (SABES)
Northern Essex Community College
45 Franklin Street
Lawrence, MA 01840
http://sabes.necc.mass.edu

See a review of this model statewide health literacy initiative in the model programs section of this report. It is considered the best developed statewide health literacy system in the United States.

Health Literacy Center, University of New England
Area Health Education Center Program
Hills Beach Road
Biddeford, ME 04005
Phone: (207) 283-0171
http://www.une.edu/com/othrdept.hlit/

The Health Literacy Center provides consulting services, workshops, and publications. They help health organizations write easy-to-read documents and train

health workers in communication skills. They do an annual workshop on Low Literacy Communication Skills for Health Professionals. Their products include *Write it Easy to Read: A Guide to Creating Plain English Materials*, multicultural clip art, and easy-to-read pamphlets. Current pamphlet topics include nutrition, tobacco, alcohol, heart disease, diabetes, HIV, women's health, mental health, family planning, injury prevention, oral health, immunizations, occupational safety, sexual harassment and more.

Health Literacy Bibliography Resources

The National Library of Medicine
Health Literacy Bibliography
http://www.nlm.nih.gov/pubs/cbm/hliteracy.html

This is one of the best bibliographies on health literacy available on line. The bibliography helps define and describe the evidence base for advancing health literacy programs. It examines theories, strategies and tactics found in the published literature. It will be useful to directors of center programs and to teachers who want program ideas, measurements and assessment instruments, resources, readability scales, and materials for special populations and cultural groups.

The National Network of Libraries of Medicine
South Central Region
http://www.nnlm.nlm.nih.gov/scr/conhlth/read.htm

This site has a very good readability analysis of consumer health materials listing for those wanting to know at what grade level their materials read.

American Academy of Family Physicians
Information from Your Doctor
http://familydoctor.org/

This site provides links to easy-to-read patient information from the American Academy of Family Physicians.

American Self-Help Clearinghouse
St. Clare's Health Services
25 Pocono Road
Denville, NJ 07834
Phone: (973) 625-3037
http://www.cmhc.com/selfhelp

"The doctor told me I had cancer. I didn't know that a mammogram would help me keep track of whether I was going to get cancer. I knew people said to check for lumps but I really didn't know why. And now I can't find the information I need to know what to do. I just hope the doctor knows what he's doing. I'll just have to leave it up to them to tell me what to do. I can't really understand all those brochures they gave me. I hope I can remember everything they tell me to do." (Mary has level I literacy skills)

The American Self-Help Clearinghouse publishes a free online directory and a reasonably priced print version to over 800 national and international self-help support groups that cover a broad range of health concerns.

Michigan Adult Learning and Technology Center
Health Literacy Online Bibliography
http://www.malt.cmich.edu/healthlit.htm

While they say they are a repeat of the Maine AHEC health literacy center bibliography, this particular source is well organized. The descriptions are useful to those looking for resources on easy-to-ready materials, health literacy problem and solutions, legal writing in plain English, the impact of marginal literacy on health and healthcare, communications planning and sources for clip art.

Limited English Language Speaker Resources

Latino Health Institute
95 Berkeley Street
Boston, MA 02116
Phone: (617) 350-6900
Fax: (617) 350-6901
TTY: (617) 350-6914
http://www.Lhi.org/

The Latino Health Institute researches, assesses and documents the health conditions of the Latino community. They develop, deliver, evaluate and disseminate culturally competent health promotion and protection programs. They encourage and enable pertinent components of the health care and social service systems to coalesce and coordinate efforts and effectively advocate on behalf of Latino residents of Massachusetts on public health issues, in close contact and collaboration with other health and human service organizations.

National Center for ESL Literacy Education
4646 40th Street, NW
Washington, DC 20016-1859
202-362-0700
ncle@cal.org
http://www.cal.org/ncle/

This is the national center for English literacy resources. Books, resource compilations, major publications, list servers and many more resources are available through this site. Health literacy is one emphasis.

National Clearinghouse for ESOL Literacy Education (NCLE)
Center for Applied Linguistics
4646 40th Street, NW
Washington DC 20014
http://www.cal.org/ncle

As the name implies NCLE has most of the major resources related to English literacy education organized for easy access. ESOL health literacy related resources are also a part of the collection.

"I have diabetes. I need to follow a restricted diet and take several medications prescribed by my family physician at regular intervals each day. I really can't read the food labels. I can't read the instructions that came with my prescription medicines. I didn't want to admit that to the doctors so I just tried to listen as good as I could. I hope I remembered the important things to do. The pharmacist was a lifesaver. He told me three times what to do and wrote out a chart for me to try to keep track of when to take which medicine. He even color-coded them for me so I could remember better."

Teachers of English to Speakers of Other Languages
700 South Washington Street Suite 200
Alexandria, VA 22314
703-836-0774
info@tesol.org
http://www.tesol.edu/

TESOL's mission is to develop the expertise of its members and others involved in teaching English to speakers of other languages to help them foster effective communication in diverse settings while respecting individuals' language rights. To this end: TESOL articulates and advances standards for professional preparation and employment, continuing education, and student programs. TESOL links groups worldwide to enhance communication among language specialists. TESOL produces high-quality programs, services and products. TESOL promotes advocacy to further the profession.

Adults with Disabilities Resources

See the U.S. DOE's Office of Vocational and Adult Education site for resources related to disabilities and adult basic education.

National Adult Literacy and Learning Disabilities Center
Academy for Educational Development
1875 Connecticut Avenue, NW, 8th Floor
Washington, DC 20009
http://www.nifl.gov/

This is a program of the National Institute for Literacy. See their web site to review the resources available through this center.

National Center for Learning Disabilities
http://www.ncld.org

This center provides national leadership in support of children and adults with learning disabilities by offering information, resources, and referral services. They also develop and support innovative educational programs, including health literacy programs. They promote public awareness and advocate for more effective policies and legislation to help individuals with learning disabilities.

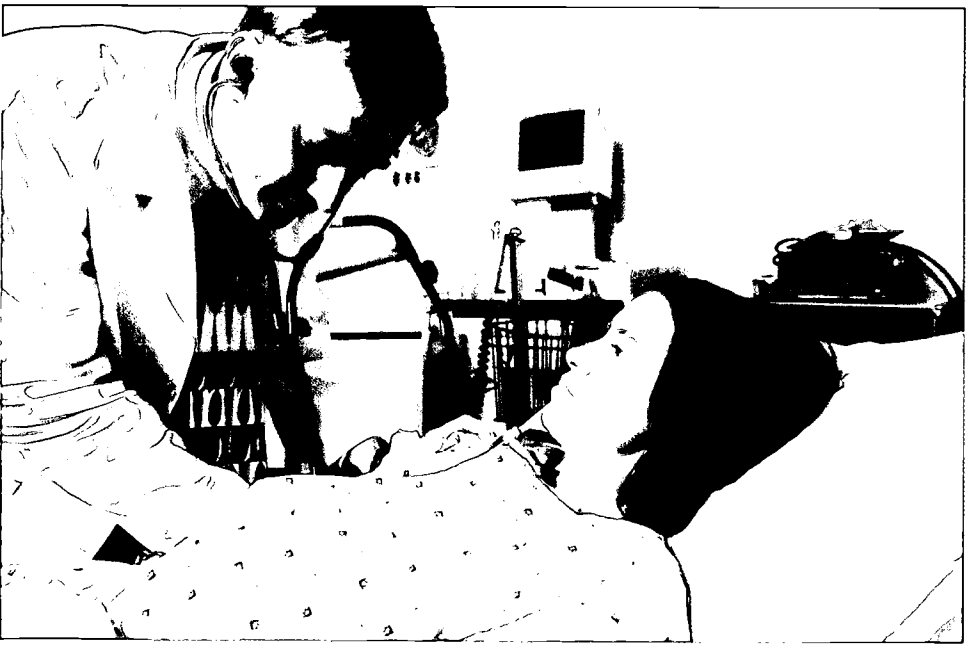
Publications

In addition to the hundreds of publications found on the sites mentioned above, the following are noteworthy.

Directory of National and State Literacy Contacts, December 1997. ED Pubs document EX0017P. Available in print and online at http://novel.nifl.gov/NSDirIndex.htm

Contact information for national and state adult education, family literacy, job training, and other offices is listed in this 241-page report. The online version is continuously updated.

Culture, Health and Literacy: A Guide to Health Education Materials for Adults with Limited English Literacy Skills, November 2000. Julie McKinney and Sabrina Kurtz-Rossi. ED Pubs document EX0129P. Available in print. This guide is designed as an addendum to the Health and Literacy Compendium and specifically contains descriptions of health education materials in English and other languages and ordering information. It also addresses issues of culture and low-literacy. Culture, Health and Literacy is intended to help health care practitioners working with patients with limited English literacy skills and adult literacy practitioners interested in incorporating health topics into adult education classrooms.



Health and Literacy Compendium,1999. World Education and the National Institute for Literacy. ED Pubs document

EX0012P. Available in print and online at http://www.worlded.org/us/health/docs/comp/ An annotated bibliography of print and web-based materials on various health-related topics for use with limited-literacy adults is provided in this 80-page publication. Some materials are available in Spanish. Organizational resources are also listed.

Empowerment Health Education in Adult Literacy: A Guide for Public Health Education in Adult Literacy Practitioners, Policy Makers and Funders, Vol. 3 No.4, Part A, 1998, Marcia Drew Hohn, Ed.D. ED Pubs document EX0028P. Available in print and online at http://www.nifl.gov/hohn/HOHN.HTM An example of how adult learners can be engaged in defining and addressing their own health care needs. The author worked with a group of women at a Massachusetts literacy center to develop student-led approaches to earlier detection of breast, cervical and testicular cancers and prevention of family violence. Background information about the relationship between literacy and health is provided.

"I can honestly say it was by far the most shameful thing that I have ever confronted in my life. You just can't imagine the hurt and the grief that you suffer by not being able to read well. For years, I thought it was something wrong with me, in my head more or less, that I could not read."

Resource with no web site listed

Education Program Associates
1 West Campbell Avenue, Suite 40
Campbell, CA 95008-1039
Phone: (408)-374-3720
Fax: (408) 374-7385

EPA includes a publications department, consulting services, and a Resource Center about health. Their publications include easy-to-read (third grade reading level and up) and culturally sensitive print and audiovisual materials about family health and multicultural health. Family health topics include family planning, sexuality, STDs, substance abuse, and childbearing. EPA's consulting services provide training in culturally and linguistically appropriate health education materials development. EPA's Health Resource Center, a membership service, provides access to over 7,000 health education materials in English, Spanish, and Asian languages that have been evaluated for reading level, audience, cultural appropriateness, translation quality and content.

Conclusion

Promoting health literacy by increasing literacy skills related to maintaining individual, family and friend's health care is an important task for both counties given the current population statistics and costs associated with low literacy rates. Literally millions of dollars per year could be applied elsewhere if health literacy rates were increased in both counties. And more importantly the quality of life of more adults in both counties and across South Carolina would be significantly enhanced.

We hope that by 2010 there is a coordinated system of health literacy services that connects public and private agencies so that any adult wanting to improve their health literacy skills can do so in a timely, cost effective manner, free from stigma, and in a useable form. We hope that leaders will move towards the development of a system of health literacy services and supports that is available so that all willing individuals in both counties are able to achieve their health learning, health maintenance and health provider goals. Chester and Lancaster counties will be better places to live, if these outcomes are realized.

If these system outcomes are achieved, then health consumers and providers in Lancaster and Chester county and all of the counties of South Carolina will be able to obtain, interpret and understand basic health information and services and have the competence to use such information and services in health-enhancing ways.[19] They will be able to obtain and manage information by proficiently using the 4 *Equipped For the Future* literacy skills sets across 13 everyday health literacy related activities.

The challenges of building such a health literacy system are difficult. It will take leaders from both counties working together in concerted ways on behalf of all residents. The South Carolina Department of Commerce bills Lancaster County as the place where you really can "have it all". Having a literate population is part of having it all![20]

Appendix

The Impacts Nationally and Locally of Low Health Literacy[21]

Low Health Literacy Skills Affect Health Status

People with low literacy are apt to: (Journal of the American Medical Association, 1995)

- die younger.
- have more health complications.
- sign medical consent forms without understanding them or being able to read them.
- not understand health providers' instructions for health care and therefore not follow instructions properly.
- be involved in workplace accidents and use unsafe practices.
- give birth to low birth weight in children.
- misuse chemical applications at home and on the job.
- see a doctor one visit more than adults with high health literacy skills (even though they self-report less visits).

People with low literacy are twice as likely to: (Archives of Family Medicine, 1996)

- be hospitalized
- report poor health.
- more likely to smoke.
- more likely to improperly read medicine labels and therefore improperly use medication.

People with low literacy are less likely to: (Kilker, 2000)

- have ever had their blood pressure checked.
- engage in regular physical activity.

People with low literacy on average: (Journal of American Medical Association, 1995)

- have 6% more hospital visits.
- stay 2 days longer in the hospital.
- report fewer doctor visits but used substantially more hospital resources.
- are subjected to more medical tests.
- have extended treatment times.
- have delayed diagnosis.
- may not know why mammograms are done or what a lump in the breast may mean. (American medical Association, 1999)

- For those who have diabetes, hypertension and asthma, health literacy skills are the strongest link to whether or not the health information received is understood and to whether or not the way one manages the disease is adequate to maintain the best health possible. This is true even if they are highly educated or low educated, rich or poor. (American medical Association, 1999)

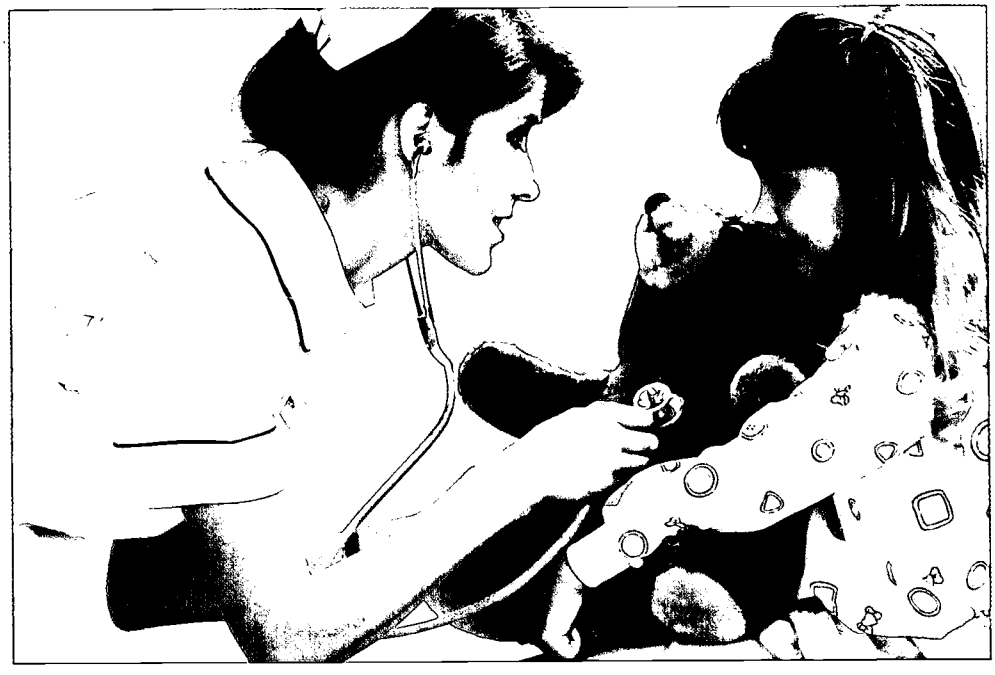
Low Health Literacy Affects Family Living and Child Well-being (Archives of Family Medicine, 1996)

- Family and friends may interpret medical instructions erroneously to the low literate member. They may be prone to omit information, add information that was not given by the doctor or nurse, substitute information, volunteer opinions that aren't medically sound, or may introduce semantic errors that distort care. Relying on family and friends rather than becoming literate has its consequences.
- Patients don't always speak freely when family members, especially children, interpret health information.
- Family interpreters might not translate accurately out of fear of the impact on the patient (family member).
- Parents with low health literacy skills are more apt to have children with low birth weight. Children who are born at a low birth weight are more likely to be enrolled in special education classes, to repeat a grade, or to fail in school. Low birth weight is a condition that may increase a child's risk of developing health, learning and behavioral problems.
- Family members can be highly educated and have a decent income and yet have low health literacy skills. Health information may not be understood in a way that promotes effective health practices. The ability to reason and problem solve relative to health issues in the family may be low, even though they can read and write at level three or higher.
- Family members who are caring for parents with low health literacy skills will experience more problems in providing needed care, care will more than likely be more expensive, and they will more than likely have greater problems in overseeing proper use of medicines and diet.

Low Health Literacy Affects Health Providers Effectiveness (Kilker, 2000)

- Most health education and promotion materials read at or above 10th grade level. This means that well over half of South Carolina's population cannot read them effectively. In Lancaster county over 56% of the population probably cannot read them effectively. In Chester county well over 60% of the population probably cannot read them effectively or at all.

- The average reading level of parents with young children is seventh or eighth grade, but 80% of the pediatric materials given to them are written at a tenth grade reading level.
- Clinicians who fail to overcome language barriers run the risk of malpractice claims arising from injuries suffered as a result of miscommunication.
- Providers also face potential claims that failure to ensure their understanding of the patient's complaints breaches professional standard of care.
- Failure to ensure that the patient understands treatment options, risks and benefits breaches informed consent requirements.
- Health care professionals receiving any kind of federal funds are legally responsible to bridge the communication gaps between themselves and their patients. (Title VI of the 1964 Civil Rights Action states: No person in the United States shall, on the grounds of race, color or national origin, be excluded from participation in, be denied benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.)



- Women (in two Atlanta GA hospitals) recently polled in two one study found that 39% read below a fourth-grade level and didn't know why women are given mammograms (compared to 12% of those reading at or above a 9th grade level). (Gazmararian, et. al. In The Journal of American medical Association, 1999)
- Patients who had inadequate reading skills did not know that mammography was associated with cancer, looking for a lump, or an examination of the breast. The public education announcements had completely escaped their understanding and attention.

Low Health Literacy Is Particularly Present Among the Poor

(National Network of Libraries of Medicine)

- Poverty is significantly linked to low literacy levels. If a person has low literacy levels they often can't do what is required to get out of poverty level conditions. Their world of opportunity is significantly limited.
- Low literacy skills are highly linked with the inability to access health care. Health care may be present but literacy levels may rob the person of the ability to access care, to understand health information, be able to operate within the health system, or to understand life style choices that affect health and well being. While people who are poor experience problems with attending appointments due to child care, transportation and/or minimum payment issues, literacy levels are an underlying reason why all these complex issues exist.

Low Health Literacy Is an Unnecessary Economic Burden

(National Academy on an Aging Society)

- Low health literacy skills increase the annual health care expenditures in the U.S. by $73 billion dollars.
- Another $11 billion are unnecessarily spent by people with low health literacy skills, primarily due to longer hospital stays. (i.e. if you have low literacy skills you are probably spending 16% more on health care than you need to for your limited income.)
- Hospitalization linked to limited literacy skills may be costing as much as $8-15 billion a year.
- Low literacy often leads to higher rates of re-hospitalization
- Incurable cancers, such as breast and cervical cancer may have been detected earlier if the patient had the ability to understand its seriousness and implications.
- Birth defects in children are significantly higher for low literate parents and some of these could have been avoided.
- The leading cause of hospitalization for women in Lancaster and Chester counties in their young adult years is due to complications with pregnancies. It is expected that at least half of these cases have underlying health literacy issues connected with their situation.
- In 2000, estimated costs associated with literacy issues for children and youth Medicaid spending in Chester County was $2.9 million. In Lancaster, the estimated costs of low literacy on Medicaid spending for children and youth is estimated conservatively to be $4.3 million.
- Conservative estimates of costs associated with low health literacy rates and emergency room visits is $7.4 million in Chester County and $14.5 million in Lancaster County for the year 2000.

- Over one third of English speaking patients at two public hospitals in the South, in a recent study, showed inadequate functional health literacy. They were unable to understand information regarding medication, appointments, and informed consent. Eighty (80%) percent of those 60 years old and above in the study had poor health literacy knowledge.
- In a study of patients in public and private substance abuse treatment centers, more than half of the public and more than a third of the private patients read below a ninth grade level.
- The Test of Functional Health Literacy in 1995 showed that 42.9% of hospital patients could not understand a tenth-grade reading level Medicaid application.

Health Literacy is Important to People with Disabilities and Their Family Members (National Center for Learning Disabilities)

- Many people with disabilities are at a higher risk for health problems. This makes understanding health and wellness information critical. Higher skills are needed to make wise health care decisions.
- A large number of people with disabilities experience difficulty reading and understanding typical consumer health information.
- Approximately 75% of American adults who report having a physical or mental health condition scored in the two lowest literacy levels of the National Adult Literacy Survey
- There are 19,895 people in Chester County and 34,619 people in Lancaster County with disabilities as reported in 1998 according to the Young Adult and Mature Adult Count reports and by the DOE for 2000.
- In 1998, 13% of children 9-17 years old were reported as seriously emotionally disturbed and 9% were extremely emotionally disturbed in Chester County. In Lancaster County, 900 youth (12%) ages 9-17 were reported as seriously emotionally disturbed and 600 (8%) were reported as extremely emotionally disturbed. (S.C. Department of Education)

Health Literacy is a Problem Connected with Seniors and Aging (National Academy on An Aging Society)

- Older adults face multiple obstacles to learning. To maintain independence and functioning, older adults have to become very good learners.
- Learning new health care information requires strong reading skills as well as strong math and problem-solving skills. Studies show that older adults often have difficulty in these three areas.
- Older adults have high rates of low health literacy because they often went to school for less years and consequently many never have acquired strong reading skills. While their oral and retention skills may be higher, they

often get health-related information from TV or listening to radio sources that might not be accurate.

- Older adults are experiencing changes in sensory and cognitive functions. This may be a result of aging or a side effect of the medications that can impair cognitive processing and problem-solving abilities.
- Older adults are often faced with multiple illnesses and problems and treating and handling these conditions are extremely complicated.
- In one study of Medicare patients in a national managed care organization, 33.9% of English speaking and 53.9% of Spanish speaking respondents had poor health literacy knowledge. (Gazmararian, et. al. Journal of American Medical Association, 1999)
- In 1990 approximately 22% of the adults 60 years of age and over had 8 years of schooling or less. That is 8.9 million people. This figure increased from the 1980 census. (2000 figures were not yet available at the time this report was written). (As report in SC Mature Adult Count)

"The patient not only failed to improve on a medication, he seemed to be deteriorating. It was discovered he was talking the wrong medication. He could not read that he had the wrong prescription, even though the bottle clearly had another patient's name on it."

A nurse telling us about one of her patient's literacy issues.

- South Carolina is one of the six states (along with California, Florida, Texas, New York and Hawaii) with the most significant number of older persons. Many of the rural areas of South Carolina are aging. In 1999 South Carolina had 473,400 residents 65+. The number has increased by 100,000 each decade since 1950. 27% of the population is 55+. There has been a 100% increase of 55+ residents since 1970.
- In Chester County 9,980 are 50+ which is a 35.8% increase from 1970. Seniors represent 28.6% of the population. 61.1% of residents 55 and older have less than a high school education. (S.C. Mature Adult Count)
- In Lancaster County 17,370 people were 50+ in 1999 which is a 92.3% increase from 1970. In 1999, 50+ seniors represented 29.2% of Lancaster's population. 61.9% of seniors 55+ have less than a high school education. (SC Mature Adult Count)

One Can Be Health Literate In One Language and Culture and Not in Another (National Institute for Literacy, Eastern LINCS)

- Individuals with limited English proficiency have cultural and language barriers that hinder understanding of South Carolina's healthcare system.
- Adults from other cultures often practice both western medical advice as well as their own cultural practices. These practices may conflict and reduce health status.
- Managing the organizational culture of the health system can be foreign to both native speakers and English as an other language speakers (ESOL).

The health system is a culture all its own. People with low literacy levels have a harder time learning how to maneuver the health care system found in the U.S., in South Carolina and in Lancaster and Chester counties.

- Unless heath literature, instructions, labels are in plan language, it is not apt to be understood by ESOL or low literate English-speaking adults.
- Some health providers lack necessary cross-cultural communication skills to effectively care for ESOL speakers, thus adding unnecessary obstacles to low literate adults' ability to follow directions and understand health issues.

Principles of Effective Educational Practice

Adults involved in helping others learn health literacy skills are effective when they do the following things.

1. They link new literacy learning to an adult's prior health consumer experience.

Adults learn more quickly if they can start with what they know and apply new learning to what they already know and can do. Educators must spend time with each adult so that they really know how they think about making health decisions, how they act as consumers and providers of health care, where they feel strong and weak in accessing the health care system and making wise health decisions for themselves and others. That's one of the reasons why using volunteers is helpful so that one thinks beyond the traditional classroom approach with one teacher and several students. Educators need to see adults actually making health decisions, trying to access health care, trying to read health instructions and follow them. Adults tend to attach more meaning to the learning that is gained when it happens connected to their own actual health decision making experiences. Adults tend to learn more quickly if they can use their own life experiences when they are literacy learners and teachers.

2. They help adults meet specific health literacy learning goals related to their own health literacy needs.

Educators must understand each adults own health literacy levels. Learning activities that *combine* basic literacy skills with practical use will enhance the adult's overall ability to become more literate. Instruction should therefore be reality-based and start by meeting immediate felt health needs and goals. Adults are ready to learn when they need to learn in order to cope with real-life health decision-making tasks or situations. There should be ample opportunity for the learners to practice their newly acquired health literacy skills. In other words, adults need to see models of health consumer acts related to health literacy skill development. They need practice in actually doing health literacy level tasks.

3. **They help adults meet specific health literacy learning goals related to their role as educator of their children's and other family member's health literacy needs.**

Adults are not only learners they are teachers too. Educators must observe the adult as teacher and coach them to educate their children and other family members to perform health literacy tasks proficiently. Learning experiences must allow adults to interact with children and family members under supervision so that adults can see other adults model effective health literacy instructional behaviors to children and family members. Adults need opportunities to be coached on how to act as educator of their children, family members and friends.

4. **Their health literacy instruction is experientially based.**

Adults learn best when they can learn by doing and then discuss what they did and how to do it better. This is called experiential learning. The educational format designed by adult literacy educators should not appear schooling-oriented in approach or style. Most schooling experiences are content-oriented rather than experientially based. And the content taught in school settings often wasn't seen as relevant by the student. In addition, schooling experiences for many level one and level two literate adults were negative experiences because failure was more their experience than success. Therefore, learning experiences for health literacy programs need to be experiential and designed to feel and look different from schooling. Instruction that uses experiential techniques, such as discussion, problem solving, simulation exercises and field experiences are more effective than lectures and rote memorization. Effective health literacy volunteers take the time to assist learning while a person is trying to understand information and learn new behaviors to tackle current health issues. Modeling behavior desired and discussed is very important so concrete examples are available.

5. **They are able to assess various learning styles of adults and communicate new health literacy information and skills to them in ways they understand it.**

They need practice in actually teaching health literacy skills to their children, friends and family members. They need to receive the necessary feedback on how to do it better. It means that the instructor must know their material well enough to go where the adult wants to go with health literacy learning rather than following the more traditional lesson plan format which follows the educators logic but not the learner's needs or logic. Why? Because adults tend to be goal oriented in their learning—they want to see results immediately. This is particularly true with health literacy learning. It is immediate because the situation is usually immediate. They want new knowledge and skill learning to applied directly to their immediate health decision-making needs as parents, worker, citizen, and health consumer. Learning must be practical and address immediate health needs that tend to be more skill-based and decision-oriented.

6. **Their literacy learning experiences are contextual.**

Often the health issue present provides the context for teaching. However, health literacy education also occurs within general discussions of skill improvement. To contextualize instruction means that the educator must learn about actual health consumer situations related to the adult efforts to gain literacy skills and act as educator of their children's and family members health literacy learning. The educator must use those situations as a base for conversations and practice. Adult learners are situation solvers. (Some call these problem solvers but not all situations are seen as problems to adults, but in fact, do demand new learning.) Once actual situations are known then teaching has a context that is seen as relevant to the adult learner. That is one reason why volunteer and natural helper advice systems and hotlines work well as part of effective health literacy education efforts.

7. **They communicate effectively with adults who have differing ways in which they think about and take action on health consumer situations.**

Adults have different learning styles and therefore the way they are taught needs to be different. Learning styles affect how we go about making sense out of information received and how we begin taking action on what we hear. It's our own thinking-action process. Some want to understand the overview first before getting to the particulars of a health situation. Others want the particulars first and then the overview. Some want as much information as they can about a health matter before they act. Others want to act or decide and then get information only relevant to what they are specifically doing. Others want to think it through completely before acting. Others want to think while acting.

"In the last week a pregnant woman was confused by the HMO handbook. She switched HMO plans and now will loose months of coverage. An asthmatic child visited our emergency room repeatedly because the instructions given to her parent were not understandable. An elderly man misread the label and took the wrong dose of medicine. A patient struggled to understand a surgical consent form. He gave up trying to read it and simply signed his name. Some consent that is! Now I wonder what kinds of liability we face if something goes wrong because I know he didn't understand what he was signing and we just let him sign anyway and proceeded to do surgery."

A nurse telling us what happened just in one week in one town in South Carolina

Some have a hard time thinking conceptually about a piece of health information. Others immediately put the information into a context based on their current health maintenance understandings and practices. Some are only comfortable hearing about it and not doing it (this seem particularly so for proper eating habits and exercise or avoiding unhealthy behaviors such as smoking). Others only want to do it and not think much about what it all means to them and others. These are all characteristics of different learning styles. Effective educators are able to adjust personal communications to match what they hear expressed in their adult learner's discussions. So instruction has to be flexible in order to pitch the health literacy message right. Because of this demand to meet multiple learning styles, having lots of volunteers to mentors one-on-one does help.

8. **They are able to work in a variety of health consumer and provider settings with a variety of different types of community leaders.**

They must partner with leaders from hospitals, clinics, nonprofit agencies, departments of health, education, social services, literacy councils, community coalition groups, churches, media outlets, the public schools, technical colleges and four year colleges and universities to develop health literacy learning sequences that can be of benefit to a greater number of adult learners. Effective adult educators can communicate with a variety of different types of people who possess differing levels of communication literacy skills.

9. **They effectively involve adults in planning their own health literacy learning.**

Learning is enhanced when there is buy in from the learners themselves. Despite more and more training and educational mandates from employers, adult learning remains primarily a voluntary exercise. Strategies, such as the development of a learning contract, seem to work well with adults. Retention is higher when adults are involved in planning their own learning.

10. **They market their health literacy learning offerings in effective ways.**

Recruitment is a problem for some. Many adult education programs run through the department of education are low in attendance because mass communication is used rather than a personal touch. Effective educators tend to set up systems

so adults are personally invited. Mass communication advertising doesn't seem to work as well. One-on-one invitations given out by an effective volunteer system or neighbor inviting neighbor, church member inviting church member, or work colleague inviting a work colleague approach tend to work better. Just think about why you choose to attend or participate in various events and functions. You are more apt to attend things when there is a personal invitation and you feel someone really cares whether or not you are there.

Another method that tends to work is building in some sort of award system. Promising a computer to any adult who comes and goes through the health literacy program has worked in some settings. Giving out books that they can use to read to their kids works for some. Providing a free office visit works. It is estimated that current literacy programs reach only about 8% of the target population.

11. **They understand that retention of adults in health literacy programs is a problem and act accordingly.**

Retention is higher in health literacy programs that have a personal touch. Adults can't feel like a faceless number. Needs have to be addressed. They have to feel comfortable and safe to communicate where they really are and what they really want to learn. They have to be given encouragement continuously. They have to experience some gains in their learning. Effective educators know this and act accordingly. Populations needing health literacy the most (ESOL, seniors, families with disabled members, low literacy individuals, those in poverty) are particularly sensitive in these regards.

12. **They reward adults who have successfully completed the program or accomplished correctly a health maintenance or decision-making task.**

In private patient care settings the rewards need to be immediate. If wiser decision making occurs, it needs to be rewarded. If health instructions are understood and followed more accurately, it needs to be rewarded. If family members counsel seniors wisely, it needs to be recognized. If medications are taken properly, it needs to be acknowledged. Immediate feedback and corrective steps are also needed.

In nonprofit settings where health education is being done there may be a longer time between the learning-reward cycle. While rewards must be ever present throughout the program, a defined end and a reward of some valued kind needs to be present. Educators therefore define the program's goals and objectives. These are obtainable and tailored to the specific group of adults with whom they are working. There are built in small "wins" to learning. These are recognized in legitimate ways. The benefit of the health literacy program should be evident to the adults.

Applying these principles is hard work. It takes thinking and acting outside the "schooling" instructional box. Recruitment and retention rates will directly correlate to how successful one is in applying these principles of teaching and communicating. Reaching learning outcomes such as those mentioned elsewhere in this report are conditioned on using these principles effectively.

Notes and References

[1] This figure is reported in most statistical reports. See the Center for Health Care Strategies and National Academy on an Aging Society at http://www.agingsociety.org/healthlit.htm as one example. This is the source used to quote.

[2] This is the definition found in the 1991 National Literacy Act. See http://www.nifl.gov/public-law/ section three.

[3] See the Equipped for the Future (EFF) report on the National Institute for Literacy site at http://www.nifl.gov/ These skills are not explained in detail within this report. Each skill listed is further defined.

[4] These figures are based on the Literacy fact sheets found on line at http://www.nifl.gov/

[5] Information courtesy of the National Institute for Literacy.

[6] This is the Joint Committee on National Health Education Standards definition of health literacy. Their definition is the most commonly used. Joint Committee on National Health Education Standards. (1995)

[7] See http://www.nifl.gov/ for the full Equipping For the Futures report, including a review of the role maps and literacy skills connected to everyday activities needed to perform effectively the role of parent, worker, citizen and health provider and consumer.

[8] A copy of the *Test of Functional Health Literacy in Adults* can be obtained by writing to Joanne Nurss, Ph.D., Research, Center for the Study of Adult Literacy, Georgia State University, University Plaza, Atlanta, GA 30303-308, phone: 404-651-2405, fax: 404-651-1415. Several versions are available: English and Spanish; short and long; large print and regular print versions. A complete guide to use is available, along with test validation and reliability information.

[9] This section, including Table 3, is based on the following references: American Medical Association, Council on Scientific Affairs, Ad Hoc Committee on Literacy. (1999). Health literacy: Report of the Council on Scientific Affairs. *The Journal of the American Medical Association*, 281, (6), 552-7; Gazmararian, J.A., Baker, D.W., Williams, M.V., Parker, R.M., Scott, T.L., Green, D.C., Fehrenbach, S.N., Ren, J. & Koplan, J.P. (1999). Health literacy among Medicare enrollees in a

managed care organization. *The Journal of the American Medical Association*, 281, 545-51; Hohn, M.D. (1998). Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders. Retrieved September 20, 2000 from the World Wide Web: http:// www.nifl.gov/; Jacobson, T.A., Thomas, D.M., Morton, F.J., Offutt,G., Shevlin, J. & Ray, S. (1999). Use of a low-literacy tool to enhance pneumococcal vaccination rates: a randomized controlled trial. *The Journal of the American Medical Association*, 282, (7), 646-650; Kefalides, P.T. (1999). Illiteracy: The silent barrier to health care. *Annals of Internal Medicine*, 130, (4), 333-336; Kilker, K. (2000) Costs of low health literacy. Health Literacy Toolbox. Retrieved September 20, 2000 from the World Wide Web: http://www.prenataled.com/healthlit/default.asp; Kirsch, I., Jungeblut, A., Jenkins, L. & Kolstad, A. (1993). *Adult literacy in America: A first look at the findings of the national adult literacy survey*. Washington DC: National Center for Education Statistics, United States Department of Education; Lee, P.P. (1999). Why literacy matters: links between reading ability and health. *Archives of Ophthalmology*, 117, 100-103; McIntosh, L. (2000) An overview of regulations addressing health literacy. Health Literacy Toolbox. Retrieved September 20, 2000 from the World Wide Web: http://www.prenataled.com/healthlit/default.asp; Nordenberg, T. (1999) New drug label spell it out simply. *Food and drug administration consumer magazine*, 99-3232 Retrieved October 7, 2000 from the World Wide Web: http://www.fda.gov/ fdac/features/1999/499_otc.html; United States Department of Health and Human Service. (2000) *Healthy people 2010*. Retrieved October 8, 2000 from the World Wide Web: http://www.health.gov/healthypeople/default.htm; Williams, M.V., Nurss, J.R., Parker, R.M. & Baker, D.W. (1998) Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension and diabetes. *Archives of Internal Medicine*, 158, 166-172; Williams, M.V., Parker, R.M., Baker, D.W., Parikh, N.S., Pitkin, K., Coates, W.C. & Nurss, J.R.. (1995). Inadequate functional health literacy among patients at two public hospitals. *The Journal of the American Medical Association*, 274, 1677-82; Williams, M.V., Baker, D.W., Honig, E., Lee, T. & Nowlen, A. (1998). Inadequate literacy is a barrier to asthma knowledge and self care. *The American College of Chest Physicians*, 114, 1008-1015.

[10] See the S.C. Literacy Resource Center's web site for details at http:// www.sclrc.org/index.html

[11] If interested contact Nedra Lisovicz, CHAN Director, The Community Health Adviser Network (CHAN), University of Southern Mississippi, Box 10015 Hattiesburg, MS 39406-0015; chan@usm.edu

[12] Taken from the National Center for the Study of Adult Learning and Literacy web site http://www.gseweb.harvard.edu/~ncsall/

[13] See http://www.nifl.gov/ for the full Equipped for the Future report.

[14] Based on the Joint Committee on National Health Education Standards definition of health literacy. (1995)

[15] This section is focused on the health literacy learning outcomes of the resident population of both counties. For those who plan to target the professional development needs of professional health providers we suggest referring to the following site for the National Health Education Standards recommended to improve student learning by providing a foundation for curriculum development, instruction and assessment of student performance. See http://www.ocps.k12.fl.us/framework/hl/strands/5.htm

[16] For a complete explanation of each of these literacy skill sets see the Equipping for the Future report at http://www.nifl.gov/

[17] See Clemson University, Institute on Family and Neighborhood Life's report on Creating Supportive Communities for Families with Young Children for a review of the basics on how to form effective collaborative efforts. It reviews the phases of community work required and the three key leadership activities that are on going in order to have effective partnerships. http://www.virtual.clemson.edu/groups/ifnl/cnd.htm

[18] Sisters of Charity Foundation of South Carolina developed a self-learning booklet on how to develop an evaluation that you might find useful. In addition, check the resources available through Amazon.

[19] Based on the Joint Committee on National Health Education Standards definition of health literacy. (1995)

[20] See http://www.teamsc.com/ Click on searchable databases. Click on community profiles and read what is said about the quality of life features in Lancaster. Strive to make the words a reality.

[21] See endnote 9 for the references on which this table is based.

Institute on Family and Neighborhood Life
Center on Neighborhood Development
Clemson University
158 Poole Agricultural Center
Clemson, SC 29634-0132

and

J. Marion Sims Foundation, Inc.
P.O. Box 818
Lancaster, S.C. 29721
803-286-8772

CLEMSON
UNIVERSITY

Public Service Activities
Research • Extension • Regulatory

Institute on Family and Neighborhood Life
Clemson University
158 Poole Agriculture Center
Clemson, SC 29634-0132
www.clemson.edu\IFNL

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)

ERIC Educational Resources Information Center
CE083354

REPRODUCTION RELEASE

(Specific Document)

I. DOCUMENT IDENTIFICATION:

Title: Promoting Health Literacy	
Author(s): Kathleen K. Wilson	
Corporate Source: Clemson University Institute on Family and Neighborhood Life	Publication Date: Fall 2001

II. REPRODUCTION RELEASE:

In order to disseminate as widely as possible timely and significant materials of interest to the educational community, documents announced in the monthly abstract journal of the ERIC system, *Resources in Education* (RIE), are usually made available to users in microfiche, reproduced paper copy, and electronic media, and sold through the ERIC Document Reproduction Service (EDRS). Credit is given to the source of each document, and, if reproduction release is granted, one of the following notices is affixed to the document.

If permission is granted to reproduce and disseminate the identified document, please CHECK ONE of the following three options and sign at the bottom of the page.

The sample sticker shown below will be affixed to all Level 1 documents

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY

Sample

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

1

Level 1 ↑ [X]

Check here for Level 1 release, permitting reproduction and dissemination in microfiche or other ERIC archival media (e.g., electronic) *and* paper copy.

The sample sticker shown below will be affixed to all Level 2A documents

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL IN MICROFICHE, AND IN ELECTRONIC MEDIA FOR ERIC COLLECTION SUBSCRIBERS ONLY, HAS BEEN GRANTED BY

Sample

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

2A

Level 2A ↑ [ ]

Check here for Level 2A release, permitting reproduction and dissemination in microfiche and in electronic media for ERIC archival collection subscribers only

The sample sticker shown below will be affixed to all Level 2B documents

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL IN MICROFICHE ONLY HAS BEEN GRANTED BY

Sample

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

2B

Level 2B ↑ [ ]

Check here for Level 2B release, permitting reproduction and dissemination in microfiche only

Documents will be processed as indicated provided reproduction quality permits.
If permission to reproduce is granted, but no box is checked, documents will be processed at Level 1.

I hereby grant to the Educational Resources Information Center (ERIC) nonexclusive permission to reproduce and disseminate this document as indicated above. Reproduction from the ERIC microfiche or electronic media by persons other than ERIC employees and its system contractors requires permission from the copyright holder. Exception is made for non-profit reproduction by libraries and other service agencies to satisfy information needs of educators in response to discrete inquiries.

Sign here, please

Signature: Kathleen K Wilson	Printed Name/Position/Title: Director, Center on Neighborhood Dev.
Organization/Address: Clemson University	Telephone: 864-656-6284 / FAX: 864-656-6909
	E-Mail Address: wilson5@clemson.edu / Date: 6/20/02

(Over)

III. DOCUMENT AVAILABILITY INFORMATION (FROM NON-ERIC SOURCE):

If permission to reproduce is not granted to ERIC, or, if you wish ERIC to cite the availability of the document from another source, please provide the following information regarding the availability of the document. (ERIC will not announce a document unless it is publicly available, and a dependable source can be specified. Contributors should also be aware that ERIC selection criteria are significantly more stringent for documents that cannot be made available through EDRS.)

Publisher/Distributor:
Address:
Price:

IV. REFERRAL OF ERIC TO COPYRIGHT/REPRODUCTION RIGHTS HOLDER:

If the right to grant this reproduction release is held by someone other than the addressee, please provide the appropriate name and address:

Name:
Address:

V. WHERE TO SEND THIS FORM:

Send this form to the following ERIC Clearinghouse:

Cheryl Grossman
Processing Coordinator
ERIC Clearinghouse on Adult, Career, and Vocational Education
Center on Education and Training for Employment
1900 Kenny Road
Columbus, OH 43210-1090

However, if solicited by the ERIC Facility, or if making an unsolicited contribution to ERIC, return this form (and the document being contributed) to: